Family and Provider Perceptions of Barriers to NGO-Based Pediatric Surgical Care in Guatemala

by

Benjamin Andrew Silverberg

Global Health Institute
Duke University

Date:_____

Approved:

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Henry Rice, Supervisor

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David Boyd, Co-Chair

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Rachel Hall-Clifford

Thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science in Global Health
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ABSTRACT

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Abstract

Background: Globally, there is often a gap between medical need and access to care, and this is particularly true for surgical care for children. In Guatemala, for instance, families frequently pursue care outside of the government health system. Using a structured anthropologic approach, we sought to explore the barriers to surgical care for children in Guatemala, suspecting both financial and cultural barriers were the primary obstacles families had to face.

Study design: Twenty-nine parents/guardians of children receiving surgical care at two non-governmental organizations (NGOs) in Guatemala and 7 health care providers participated in semi-structured interviews to explore what they believed to be the impediments to care. Transcripts were analyzed using a grounded theory approach. Current models for barriers to care were critiqued and a novel Framework for Barriers to Pediatric Surgery in Guatemala (FBPSG) was developed, which highlights both the existence, and centrality, of fear and mistrust in families' experience.

Results: Families and providers identified financial costs, geography, and systems limitations as the primary barriers to care. Mistrust and fear were also voiced. In addition, health literacy and cultural issues were also thought to be relevant by providers.

Conclusions: Due to biases inherent in this sample, parents/guardians did not necessarily report the same perceived barriers as healthcare providers – e.g., education/health literacy and language – and may have represented a "best case" scenario compared to more disadvantaged populations in this specific Central American context. Nonetheless, financial concerns were some of the most salient barriers for families seeking pediatric surgical care in Guatemala, with systems limitations (waiting time) and geographic factors (distance/transit) also being highlighted. Fear and mistrust were found to be deeper barriers to care and warrant reevaluation of organizational heuristics to date. NGOs can address these worries by working with individuals and organizations already known by and trusted in target communities and by providing good quality medical treatment and interpersonal care.

Dedication

This thesis is dedicated to my mother, the elder Dr. Silverberg, who has been my first – and best – teacher.

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I would like to thank my faculty committee members Dr. Henry Rice, Dr. Rachel Hall-Clifford, and Dr. David Boyd for their thoughtful edits of this manuscript, professional mentorship, and life advice over the last 2 years. I would also like to thank Stephanie Roche for on-the-job training and peer mentorship; Dr. Helmut Denker, Dr. Xavier Emilio Tomala Haz, and Rafael Tercero for help with translation; Ariel Bernardo Marroquin Garcia, Dr. Juan Manuel Ramirez, Marta Gomez Xicay, Leo Fife, Maria Jose de Gallardo, Dr. Ligia Figueroa, and Tessa de Goede for in-country support; Lysa Mackeen, Sarah Martin, Michael Russell, Dr. Chris Woods, Dr. Kearsley Stewart, Dr. Bethzaida Fernández, and Dr. Jay Pearson for academic support; Vivien Needham for office support; and the Andrew W. Mellon Foundation and the Duke Center for Latin American and Caribbean Studies for financial support for travel.

1. Introduction

Receipt of medical or surgical services requires both the existence of systems for health and access to them. Conservative estimates report that surgically-treatable conditions account for 11% of the world's global burden of disease, resulting in loss of over 1,400 million disability-adjusted life years (DALYs) annually [DEBAS 2006]. Though surgery has the potential to save lives and prevent disability, in low- and middle-income countries (LMICs), such care is usually found only in urban centers, where it is viewed as an expensive luxury [BICKLER 2002, FARMER 2008]. Data on the cost-effectiveness of surgical care in LMICs is sparse, and the barriers to care are not always clear. Consequently, public and global health efforts often neglect the discipline altogether, further deepening the schism between need and access [DEBAS 2006, FARMER 2008, BICKLER 2010]. Financial barriers to care are commonly reported, but cultural barriers are often forgotten as they are harder to quantify and understand.

1.1 Need, Access, and Barriers

The field of global health has emerged relatively recently, influenced by public health, economics, and anthropology; evolved from international health; and promising to transcend political boundaries [MERSON 2012, SKOLNIK 2012]. It reflects a changing planet: Globalization has simultaneously made the world much smaller (e.g., a mutated virus can be transported from China to Canada just as easily as an epidemiologist trying to track it) and larger (e.g., only now are we starting to take

collective responsibility for the individual actions that have caused health inequities and global warming) [HARDIN 1968, DYAR 2011, MERSON 2012]. Unfortunately, with a lack of consensus on what "global health" actually means, let alone its aims, we run the risk of forming an incomplete picture of this multidisciplinary area, potentially excluding key elements [DYAR 2011]. With its strong roots in tropical medicine and infectious disease, despite the evolution of the discipline, our minds typically remain fixed on the same two white and black horsemen, Pestilence and Famine, when we conjure up visions about what global health actually entails. Campaigns to feed, hydrate, or immunize poor, dark-skinned, rural youths have literally become the poster children for global health, leaving other efforts neglected.

Surgical care is one such forgotten element, as Paul Farmer, Harvard physician-cum-anthropologist and Duke University alumnus, lamented in his 2008 essay with colleague Jim Kim. In calling surgery "the neglected stepchild of global public health," they succinctly describe the specialty as a non-blood relative, an "add-on" usually excluded from family photos [FARMER 2008]. In part, this may be because surgery is actually hidden in plain view: Operative procedures can address a variety of treatable conditions – open debridement of infected wounds, coronary bypass to circumvent cholesterol-clogged vessels, and reduction and fixation of broken bones from a traffic accident, for example. Thus, surgery traverses the three classic genres of disease and malady – communicable diseases, non-communicable diseases, and injuries – but is the

flag-carrier for none. Without intervention, though, these problems add to the burden of poor health for individuals and populations [DEBAS 2006]. Unfortunately, in many countries with developing economies, surgical care is simply not considered part of public health, let alone a priority. "Careful scrutiny of local inequalities of risk and access to care reveals that in poor countries, even minor surgical pathologies are often transformed through time and inattention into lethal conditions," Farmer and Kim write. "Congenital abnormalities such as cleft palate remain life-long afflictions rather than pediatric surgical disease" [FARMER 2008].

Traditional views of what are the most pressing (or visible) health issues in developing countries are not the only reason why laypersons and policy-makers alike may fail to recognize the importance and power of surgery. Farmer and Kim point out that the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM) does not find a parallel Global Fund for Surgery, for instance, though many individuals are involved with smaller projects [FARMER 2008]. Further, local infrastructure makes it difficult for those in need to connect with those who are able to help. Where it does exist, there are still great disparities in who is able to access this "life-saving and disability-preventing" care [IRFAN 2012]. Surgical services are usually based in urban centers and available only to those with the financial resources to pay for them [FARMER 2008]. Thus, "the poorest third of our world's population receive only 3.5% of the total number of surgeries performed yearly" [IRFAN 2012].

Tucked away in the 67th chapter (of 73) of Disease Control Priorities in Developing Countries, Haile Debas and his colleagues review four specific types of surgical intervention that can affect public health: initial care to victims of injury; management of obstetric complications; handling of emergent, life-threatening conditions, especially in the abdomen; and elective care of "simple" surgical conditions (eg, hernias, clubfoot, cataracts, hydroceles, and otitis media) [DEBAS 2006]. "No matter how successful prevention strategies are," Debas writes, "surgical conditions will always account for a significant portion of a population's disease burden, particularly in developing countries where conservative management is not readily available, where the incident of trauma and obstetrical complications is high, and where there is a huge backlog of untreated surgical diseases" [DEBAS 2006]. In other words, even in the most careful environment, surgery will always have a role in secondary or tertiary prevention of long-term sequelae and disability.

Injuries and congenital anomalies are of particular importance to pediatric health care. It is often said that children are not just little adults, but this now-obvious cliché is still relevant in surgery. "Children develop distinct surgical conditions, present unique anesthetic challenges, and have special perioperative needs," write Bickler and Rode. "Moreover, the consequences of pediatric surgical conditions may be lifelong since they affect children at critical times during development" [BICKLER 2002]. Children in the developing world in particular are victims of circumstance. Surgery is considered as

falling outside the domain of "basic health care," and neither the causes of surgical problems nor the disability caused by failing to treat them are considered priorities. In Africa, for instance, child safety is viewed with little concern and injuries account for approximately 50% of surgical conditions there. Congenital anomalies are common and underreported, though they account for nearly 25% of surgical issues [BICKLER 2002]. As a consequence, pediatric morbidity and mortality are likely higher than they need be. Unfortunately, published data are scarce.

The fraction of children that do potentially have access to surgical care are faced with additional problems: A lack of qualified pediatric surgeons means families may have to travel even further and longer than older would-be patients to reach an appropriate facility. The cost of transportation imposes an additional considerable burden on caregivers [BICKLER 2002]. Once those barriers have been surmounted, children and their families may be greeted by overwhelmed and undertrained staff, insufficient and broken equipment, and severely limited pharmacies [BICKLER 2002]. With inadequate institutional capacity, individuals with non-emergent conditions face further delays or may be turned away, leading to disenfranchisement with the health care system. Similarly, suboptimal care may result in poor health outcomes, which both damages communities' trust and potentially creates more work for an already bursting system.

In these ways, pediatric surgical care is both similar to and different from care for adults. Since prevalence of surgically-correctable conditions is likely underreported and, further, various barriers limit access to care, health care policy in the developing world simply does not reflect surgical need nor address the widening gap between need and access [BICKLER 2002]. Writing in the context of improving pediatric surgical care, Bickler and Rode make four key recommendations that are applicable to other weaknesses in health care systems globally: (1) demonstrate and document a need for this type of care, (2) define a cost-effective essential package of services, (3) improve care at the community level, and (4) provide better training for healthcare workers, and, ostensibly, for the public [BICKLER 2002].

The first half of Bicker and Rode's advice focuses on data: Show that the burden exists and that treating it, at least from a policy standpoint, is worth the financial investment. The burden of surgical conditions, or "the disability and premature death that would exist in a population without any surgical care," is the composite of unpreventable, actual, and potential disability-adjusted life years (DALYs), or, put another way, unmeetable, unmet, and met need [BICKLER 2010]. Debas et al. estimate 11% of the world's DALYs are from surgical conditions, and Farmer and Kim report it may be upwards of 15% [DEBAS 2006, FARMER 2008]. Of these, injuries constitute the greatest specific burden: 4.3% of total DALYs (38% of surgical DALYs) or 63 million DALYs. Malignancies and "other conditions" tie for second place, representing 2.1% of

total DALYs each. Assuming about 50% of these conditions are operable, congenital anomalies, "an ill-defined grouping of separate pathologies that includes congenital malformations such as cleft lip and palate, hernias, anorectal malformations, and clubfoot," represent 1% of total DALYs (9% of surgical DALYs) [DEBAS 2006].

From here, however, sparse data only grow thinner. Appropriate care does not just begin and end at the door to the operating room; it involves an organized network of community-based clinics, district hospitals, and tertiary care hospitals. Ideally, it also includes "wireless communication; continuing education programs; regionalized supply system for equipment, essential drugs, and surgical materials; ambulance service; uniform data collection system; coordinated and ongoing monitoring of quality and outcomes of care" [DEBAS 2006]. With so many variables, data on the cost-effectiveness of specific surgical interventions, their timing (i.e., whether it is financially more appropriate to treat certain conditions electively or wait until they develop emergent complications), and even surgical wards themselves are either unreliable, hard to find, or non-existent [DEBAS 2006]. Debas et al. write, "The literature on surgical care in developing countries is so meager that insufficient data are available to formulate an agenda for research and development. Hence, of necessity, the research that needs to be done is extremely basic, much of it information gathering" [DEBAS 2006].

They do share some optimism, however, stating that "surgical services have a cost-effective role in population-based health care. Recent studies show that basic

hospital service, which requires no sophisticated care, can be cost effective, with a cost per disability-adjusted life year (DALY) that is much lower than might have been expected, and can be on par with other preventative procedures, such as immunization for measles and tetanus and home care for lower respiratory infections" [DEBAS 2006]. The cost per surgical DALY averted is lower at district hospitals (estimated between $19 and $164 USD, cheapest in sub-Saharan Africa and most expensive in Latin American and the Caribbean) than community health centers (estimated between $212 and $241 USD) [DEBAS 2006].

The cost of care to the health system is a moot point, though, if no one is able to access it. This is perhaps the greatest disparity lies: between need (surgical burden) and access. Consequently, exploration of the barriers to care has been a focal area of research in recent years. The RAND Corporation – an independent nonprofit research institution whose name is originated as a contraction of "Research and Development" – defines access to healthcare facilities as "the ease with which a patient can gain entry to or utilize health care in the face of financial, geographical, organizational, cultural, and emotional barriers" [qtd. in CHANDRAN 2011]. Though major components or dimensions of access have been phrased differently by other authors, they ultimately reflect the same ideas. Brigit Obrist and her colleagues, for example, echoed other frameworks in citing the affordability, availability, and acceptability of care, but went further in suggesting accessibility and adequacy are important, too [OBRIST 2007,

IRFAN 2012]. In other words, care should be priced in line with clients' ability to pay, meet their needs, be culturally-sensitive, be in a reasonable location, and meet their expectations, respectively [OBRIST 2007].

Access and utilization are sometimes, incorrectly, used interchangeably. Access refers to potential access – "when a disadvantaged individual lives in a place at a time when a capable healthcare delivery system is available" – and utilization is the only available proxy for "actual" or "realized" access [CHANDRAN 2011]. Though this definition clarifies the nuance, it opens up argument about the concept of vulnerability. Ann Cronin and her colleagues write, "it remains the case that much of the research on vulnerability has been underpinned by a deficit model which assumes that some groups of people are more vulnerable than others because they lack something... Undoubtedly the uneven distribution of economic, social, and political power in society leads to certain groups of people being at greater risk of adverse events such as ill-health, trauma, or material loss. However, this one-sided approach tells us very little about the experiential nature either of being a member of such a group or feeling vulnerable" [CRONIN 2008]. She adds that by calling one group "vulnerable," it is implied that another is "not vulnerable," a binary classification that fails to consider how people experience daily challenges.

One of the first – and most frequently used – frameworks to conceptualize healthcare access, Andersen's behavioral model (1968), considered both positive and

negative phenomena en route to the use of health services: predisposing factors, enabling resources, and need [ANDERSEN 1995]. Though Andersen's model has been expanded and adapted over the years to include other elements – e.g., the "environment" (the health care system and external environment) – it remains that the individual is the unit of analysis [CARRILLO 2011]. Other models have focused squarely on barriers. Expanding upon a model proposed by Jennifer DeVoe and her colleagues (2007), J. Emilio Carrillo and has colleagues developed the Health Care Access Barriers Model (HCAB), which "describes 3 categories of modifiable health access barriers: financial [e.g., cost of care/insurance], structural [e.g., institutional and organizational barriers such as proximity and transportation], and cognitive [e.g., knowledge and communication barriers] (Figure 1) [CARRILLO 2011]. What is unique about this model – besides the fact that it treats barriers, not individuals, as the unit of analysis – is it is meant to focus on what is changeable or mutable, which "facilitates root-cause analysis and intervention design" [CARRILLO 2011]. Specifically considering barriers to surgical care in LMICs, Caris Grimes and her colleagues describe similar categories: social/cultural, financial, and structural [GRIMES 2011, IRFAN 2012].

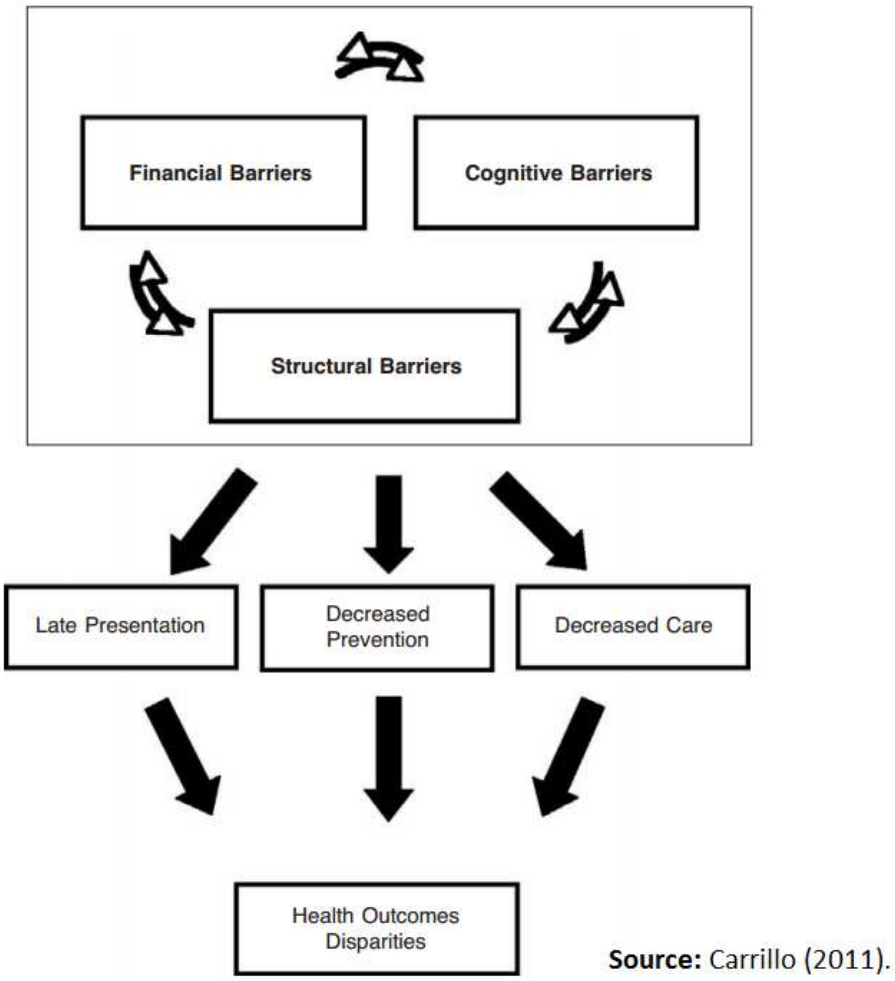


Figure 1: Health Care Access Barriers (HCAB) Model.

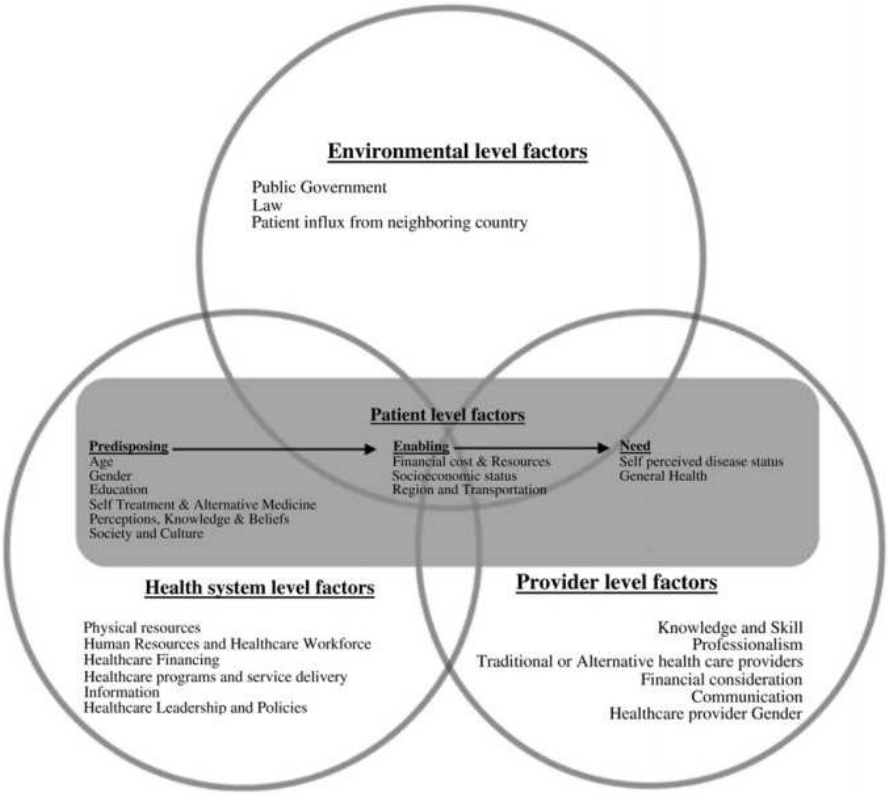
Kathryn Derose, a senior policy researcher at RAND, and her colleagues emphasize that community-level factors affect disparities in health care access [DEROSE 2011]. "Access to health care services requires both socio-organizational (aspatial) and geographic (spatial) access," writes Karen Owen and her colleagues [OWEN 2010]. Indeed, physical and social environments influence behavior (i.e., "context matters") [GAGE 2007]. Other authors have considered social networks and information

asymmetry, for instance, but perhaps the most striking and uncomfortable contextual concept is that of structural violence, “the social machinery of oppression” [FARMER 2004]. Paul Farmer describes this as “social structures characterized by poverty and steep grades of social inequality, including racism and gender inequality” and notes the disconnect between this social force and individual morality [FARMER 2004].

However, measuring macro-level variables is difficult: They may not be readily available, and trying to relate them to individual data often requires personal identifiers [PHILLIPS 1998]. “Environmental variables are often measures at an aggregate level, for example, state-level policies,” writes Kathryn Phillips and her colleagues, “where utilization is generally measured at an individual level” [PHILLIPS 1998]. In trying to improve upon Andersen's model, she conducted a systematic literature review of 139 articles using the behavioral model. She found that 45% included environmental variables and 51% included provider-related variables [PHILLIPS 1998]. “As with environmental variables, researchers may not include provider-related variables because they are not readily available. For example, we did not find any studies in our sample that included the out-of-pocket price of services, which is a key variable from an economic perspective,” she writes [PHILLIPS 1998]. To fill in this gap, Furqan Irfan and his colleagues further adapted Phillips's modification of Andersen's model by adding in the World Health Organization's (WHO) health system building blocks. The result, the Healthcare Barrier Model (HCB), is an integration of models – rather than a new, stand-

alone framework – that focuses on 4 domains: the patient, the provider, the environment, and the health system (Figure 2) [IRFAN 2012]. In comparison to Carrillo's and Grimes's models, it may be somewhat easier to ascribe barriers to a particular actor in the health care system.

Irfan specifically applied his model to surgical care. In performing a literature review, however, he found that most studies were retrospective and quantitative, and that across all LMICs, only 52 were qualitative [GRIMES 2011, IRFAN 2012]. Using a similar set of domains to organize barriers, Emmanuel Scheppers and his colleagues found that of the 54 articles they reviewed, 28 were quantitative, 10 were qualitative, and 6 were mixed [SCHEPPERS 2006]. Though qualitative methods may be better at uncovering contextual details, Irfan noted that such studies are subject to reporting bias ("authors may choose to depict only those barrier themes that they assume to be of relevance"), making them "specific but not sensitive to identification of barriers" [IRFAN 2012]. Local cultural beliefs, for example, are one important aspect of health care access and utilization that other authors have discovered through interviews [WATKINS 2002, BHOSAI 2011]. Further, it is "qualitative discourse analysis" that allows creation of experientially-based models that may predict future behavior [SOBO 2006].



Source: Irfan (2012)

Figure 2: Healthcare Barrier (HCB) Model.

Patient experience is not synonymous with patient expectations [SOBO 2006]. Healthcare providers are in a unique position to shape a positive experience for the patient and his or her family, even in unpleasant an unpleasant environment or health system. Thus, enumerating, organizing, and understanding barriers to healthcare utilization can help providers avoid common pitfalls or creation of certain barriers in the first place [SCHEPPERS 2006].

1.2 The Guatemalan Context

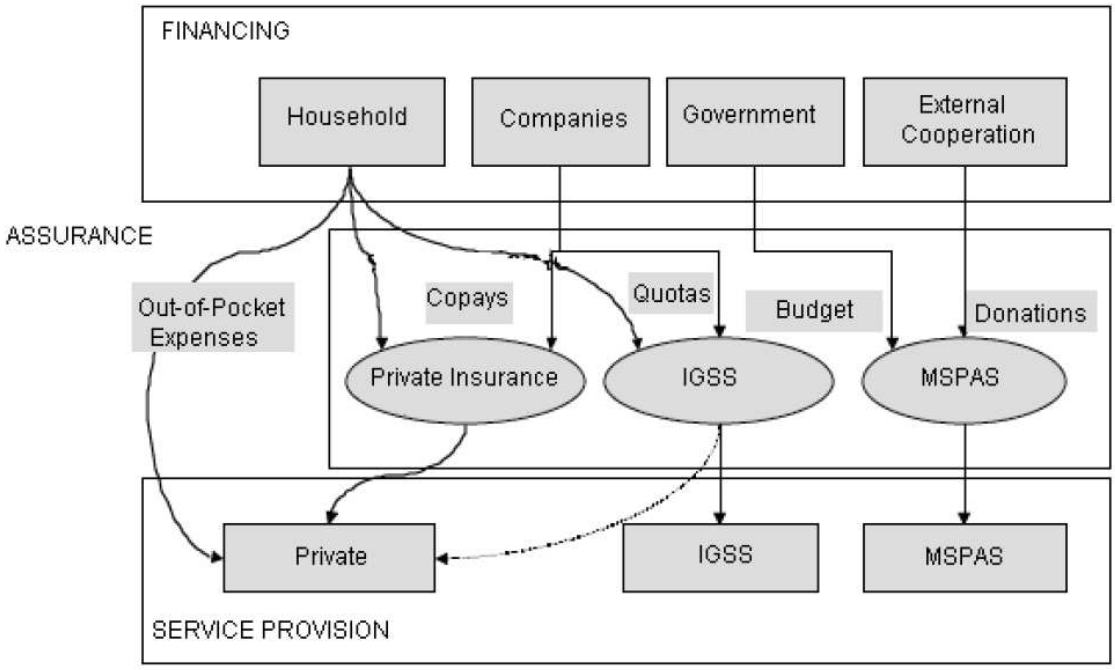
With a population of over 15 million (2012 data), Guatemala is the most populous country in Central America but one of the poorest in the whole of the Latin American and Caribbean (LAC) region [BOWSER 2011, WORLD BANK 2014]. Fifty-three-point-seven percent of the population lives at or below the national poverty line (2011 data) [WORLD BANK 2014]. It also has some of the widest health disparities in the region: The health inequalities index (INIQUIS), a composite measure based on life expectancy at birth, maternal mortality, density of physicians, and other similar indicators, is 0.5809, ranking only behind Haiti, and the Gini coefficient is 0.585, the worst in the region (though the data for Haiti was not reported for this time period, 2005-2010) [CARDONA 2013]. Life expectancy at birth is 71 years (2011 data) [WORLD BANK 2014]. Indigenous Maya comprise about 50% of the population, though that figure swings between about 40% and 60% depending on how this group is quantified (i.e., whether it is on the basis of self-identification, language, clothing, or the like) and ulterior motives [PAHO 2007, MRGI 2008, IWGIA 2013]. Over 20 ethno-linguistic groups make up the indigenous population, with most concentrated in the western highlands [MRGI 2008]. Non-indigenous individuals are called ladinos/ladinas or mestizos, meant to reflect a peninsular Hispanic heritage. Chronic malnutrition has a 55.5% prevalence in rural areas and 36.5% prevalence in urban areas [PAHO 2007]. Based on infant and child

mortality data, the rural indigenous population is thought to be the most vulnerable social group in Guatemala [PAHO 2007].

It is important to remember that these statistics are in the context of a country still recovering from civil war: The 36 year conflict (1960-1996) fought between government paramilitary forces and leftist rebels resulted in approximately 200,000 deaths and "disappearances" of indigenous Maya, rural peasants, and intellectuals. Former government officials and leaders have recently been tried and convicted of human rights abuses and participation in genocide, and posters of the missing still line certain streets of the capital.

Social factors are not the only determinants of health. The country's topography combined with rainy and dry seasons puts certain areas at risk of floods, landslides, and droughts, and volcanoes and earthquakes affect still others [PAHO 2007]. Government spending on health is relatively low, 1.9% of the gross domestic product (GDP), and public spending is the second lowest the LAC region [BOWSER 2011]. Health insurance is uncommon, and poor Guatemalans in particular are susceptible to health shocks due to out-of-pocket spending and/or income losses [BOWSER 2011]. Diana Bowser and Ajay Mahal report that nearly 40% of Guatemalans do not have access to health care services [BOWSER 2011], and Karen Owen and her colleagues cite a study done about 30 years ago that claimed "one hour of travel time was deemed to be a reasonable definition of access" [OWEN 2010].

Health care services are typically divided into primary, secondary, and tertiary strata. In Guatemala, these consist of government-run health posts (puestos de salud) which can be staffed by any level of provider, and remote outposts maintained by NGOs (jurisdicciones); health centers staffed by physicians (centros de salud); and hospitals (hospitales), respectively [PAHO 2007]. Three different sectors manage facilities in these various levels of care (Figure 3): the government (the Ministry of Public Health and Social Welfare, or MSPAS), a social insurance organization (the Guatemalan Social Security Institute, IGSS), and the private sector [PAHO 2007, BOWSER 2011].



Original source: MSPAS. Protección Social en Salud: guatemala, Informe Final, 2002.
Reprinted from: PAHO. Health systems profile of Guatemala, 2007.

Figure 3: Diagram of health care financing and provision in Guatemala.

Unfortunately, despite a growing population, health capacity in recent years has not increased [PAHO 2007]. MSPAS, whose services range from primary to tertiary care, can be found in rural and urban locations and generally offers care free of charge [BOWSER 2011]. As of 2005, it featured a total bed capacity of 6030 [BOWSER 2011]. The majority of MSPAS facilities were built 30 years ago or more, and the MSPAS annual budget may not be sufficient to maintain and replace equipment, let alone improve infrastructure or introduce new technology [PAHO 2007]. Fifty-four percent of the population is covered by the MSPAS network [PAHO 2007], and, in 1996, the Integrated Health Care System (SIAS) was introduced to expand basic health care services to those without access, particularly the indigenous [PAHO 2007, BOWSER 2011]. With SIAS, the government has contracted out financing and delivery of certain health services to an NGO, "a central strategy of neoliberal health reforms in Central America" and "a potential mechanism to redefine antagonistic relationships between the state and civil society, particularly in countries ravaged by political violence... potentially facilitat[ing] decentralization and civil participation" [MAUPIN 2009].

The IGSS is only available to those with formal employment who pay into it, with spouses and young children getting some modest services by extension [BOWSER 2011]. Two-thirds of workers are not eligible for IGSS, however, and its services are mainly found in urban areas [PAHO 2007, BOWSER 2011]. The private sector is increasing, both with for-profit (e.g., private insurance, hospitals, clinics, pharmacies,

and laboratories) and not-for-profit (e.g., traditional medicine and over 150 NGOs) institutions [NGUYEN 2013, PAHO 2007, BOWSER 2011]. To be sure, despite having to pay out-of-pocket – less than 5% of Guatemalans are covered by private insurance – many Guatemalans seek care from the private sector [NGUYEN 2013, BOWSER 2011]. Overall, individual households are the primary source of health financing (69%), with government spending slowly declining (18%) and international aid providing a mere fraction (2%) [BOWSER 2011].

NGOs – government-contracted efforts like SIAS or private organizations alike – attempt to reduce barriers to access through subsidized services and/or delivery of care in underserved communities. One of the first NGOs in Guatemala was a medical program in the mainly indigenous department of Chimaltenango led by Dr. Carroll Behrhorst in 1962. Though he attempted to maintain neutrality in the conflict between paramilitary forces and guerrillas, focusing on delivery of health care, many of his health promoters were killed in the 1980s [BEHRHORST 2014]. Thus, NGO involvement in Guatemala began on somewhat unstable footing.

Though the exact burden of pediatric surgical disease in Guatemala is unknown, inadequate government-supported care implies that not all who would need care are able to obtain it [NGUYEN 2013]. NGOs have stepped in to help fill this gap: Visiting teams of healthcare providers cooperate with Guatemalan colleagues to screen patients and provide appropriate surgical care for free or at reduced cost. The impacts of these

"donated" surgeries (e.g., whether this breeds dependence on foreign providers) remain unclear, however [OZGEDIZ 2009]. Thus, it is important to study this specific aspect of the Guatemalan health care system further.

Research supervised by Rachel Hall-Clifford has explored barriers to care as perceived by representatives from NGOs and patients themselves through semi-structured interviews: Those working with NGOs worried about financial and cultural barriers and a lack of post-operative follow-up care [GARRETT 2011]. From the perspective of patients and their families, the "critical themes impacting successful treatment-seeking and patient satisfaction included transportation, waiting time, medical costs, and communication of information" [BROCKINGTON 2013]. Kathryn Jacobsen and Andrea Bankoski, also studying surgical care in Guatemala, performed a retrospective chart review of 474 adult patients and 216 pediatric patients. They found that (1) patients were more likely to follow through with their plan of care if there were shorter delays between screening and surgery, (2) patients and their families were also more likely to be compliant if an adult in the family knew someone who had undergone surgery successfully, and (3) children were more likely to receive needed surgical care if they had a parent/caregiver who spoke Spanish [JACOBSEN 2010]. "Qualitative studies of indigenous residents in or adjacent to the [NGO's] catchment area have found that not speaking Spanish is a major barrier to seeking medical care, in part because of the perception that healthcare workers may provider a lower level of care to indigenous

patients" [JACOBSEN 2010]. Karissa Nguyen and her colleagues reported similar issues upon completing a quantitative study of 78 families of Guatemalan children receiving outpatient surgical care to improve their quality of life. Citing an inefficient national health care system, mistrust of local healthcare providers, limited financial sources, and less well-defined cultural barriers, she noted that "identifying specific barriers to pediatric surgical care is a necessary first step to improving health care delivery" [NGUYEN 2013].

"Cultural barriers" is a poorly-defined category that warrants further exploration, and potentially the best approach is to talk with those who are most affected, try to uncover what is not working, and adapt the system. Qualitative analysis may lead to deeper understanding, going "beyond the traditional association of marker variables with poor outcomes ("what") to reveal an understanding of processes by which parents develop the health care system ("how," "why") and by which disparities may arise" [SOBO 2006, parentheticals original]. This endorsement agrees with Phillip's call for "studies that are designed to examine contextual factors" as well as attempts to fill in gaps in data (e.g., actual out-of-pocket costs) [PHILLIPS 1998].

1.3 Summary

In the lower-middle income country of Guatemala, 1 out of every 2 people lives in poverty [WORLD BANK 2014]. Indigenous Maya, who are more likely to be rural peasants and, separately, suffer discrimination than their ladino (non-indigenous)

counterparts, comprise approximately 50% of the population, though this estimate is frequently disputed as being too high or too low [FARMER 2004]. Healthcare is provided through several different resources within the private and public sectors and at the primary, secondary, and tertiary levels (health posts, health centers, and hospitals, respectively). Private insurance is uncommon and entry to private clinics is usually contingent on out-of-pocket payments [NGUYEN 2013, BOWSER 2011]. Facilities operated by the Guatemalan Social Security Institute (IGSS) provide care only to those with formal employment who pay into it [PAHO 2007, BOWSER 2011]. Government-operated facilities (the Ministry of Public Health and Social Welfare, MSPAS) are generally free of charge but still only cover 54% of the population [PAHO 2007]. Further, more than half of MSPAS hospitals are older constructions and operate on low budgets that may not support maintenance of existing equipment, let alone improvement [PAHO 2007].

Health capacity has not much increased in recent decades and there is still significant unmet need, particularly for surgical care [PAHO 2007, BOWSER 2011]. International groups, supported by non-governmental organizations (NGOs), often fill these ongoing gaps, providing access to surgical care meant to improve lives (e.g., cleft palate/lip repair) [NGUYEN 2013]. Short medical missions (jornadas) screen patients for surgical conditions both in the field and in established hospitals and coordinate appropriate surgical treatment. Despite this care being free or low-cost, a significant

portion of Guatemalans still do not receive surgical care [JACOBSEN 2010]. Our previous work as well as that of others based on epidemiologic surveys has suggested that financial factors are among the most important self-identified barrier for families seeking surgical care, though other structural or cultural barriers – such as trust, local quality of care, language, and religious and health beliefs – may also be relevant [NGUYEN 2013, KRONFOL 2012].

The majority of studies of barriers to surgical care are quantitative in design, and though they yield comprehensive lists, they are usually based on relatively imprecise surveys [SCHEPPERS 2006]. Generalities in meta-analyses often make it difficult to make specific policy recommendations for particular communities [SCHEPPERS 2006]. Consequently, social scientists have developed various taxonomic schemata to study and categorize these barriers in greater detail. Irfan's Healthcare Barrier Model (HCB), for example, itself an adaptation of Phillip's modification of Andersen's behavioral model of utilization, enumerates factors at the environmental, health system, provider, and patient levels [ANDERSEN 1995, PHILLIPS 1998, IRFAN 2012], whereas the Health Care Access Barriers Model (HCAB) considers financial, cognitive, and structural barriers in an effort to explain disparities in health outcomes [CARRILLO 2011]. These models are highly dependent on the cultural and socioeconomic context and do not necessarily reflect the relative importance of each obstacle as individuals and their families navigate the healthcare system, however.

In this study, we sought to critically examine the different barriers to surgical care using structured qualitative anthropologic research methods. We focused on patients receiving care from NGOs for 2 reasons: One, the impact of these organizations in the greater health system is unclear, and two, with their typically smaller patient volumes and higher operating budgets, NGOs may be in a better position to adjust their delivery systems based on result findings. We predicted that financial concerns would be the primary perceived barrier to surgical care. We also sought to tease apart the unique cultural issues impacting families' experiences seeking surgery in Guatemala. To test this hypothesis, we conducted semi-structured interviews with parents/guardians and healthcare providers of Guatemalan pediatric surgical patients, using grounded theory to explore common themes and motifs regarding access to pediatric surgical care in this population.

2. Methods

The preparation of this research effort, data collection, and analysis was divided among members of the research team, which consisted of a primary care provider and student in global health (BAS), a surgeon (HR), an anthropologist (RHC), an expert in global health and cross-cultural medicine (DB), and a student in public health (SR) (Table 1).

Table 1: Division of tasks among research team.

Research component	Researcher(s)
Interview instrument	
Initial writing	BAS
Revision, pre-pilot testing	RHC
Revision, post-pilot testing	SR, BAS
Semi-structured interviews	
Family interviews (n = 29)	
4/29 (completed with 2 researchers present)	SR, BAS
23/29	BAS
2/29	SR
Provider interviews (n = 7) †	
3/7 (completed with 2 researchers present)	SR, BAS
3/7	BAS
1/7	SR
Codebook	
Development	BAS
Revision of codes	RHC
Coding of data	BAS
Manuscript	
Initial writing	BAS
Feedback and revisions	HR, RHC, DB
† N.B. 1 provider participated by using the interview tool as a survey	

2.1 Participating Clinical Sites/NGOs

Research subjects were recruited from 3 NGOs providing free or low-cost surgical care in Guatemala: the Moore Pediatric Surgical Center (Centro Quirúrgico Pediatrico Moore) in Guatemala City; Hermano Pedro Obras Sociales, a Catholic charity hospital in Antigua Guatemala; and Partner for Surgery (Asociación Compañero para Cirugía) in nearby San Lucas (Table 2). Whereas, at the time of this study, the Moore Pediatric Surgical Center and Hermano Pedro Obras Sociales had fixed clinical facilities, performing both screening and surgical care on site, Partner for Surgery conducted its medical missions in more remote communities, away from its main administrative office. Four of the 5 healthcare providers affiliated with Partner for Surgery who were interviewed in this study most recently returned from a jornada in the department of Alta Verapaz, nearly 200 miles north of Guatemala City (Figure 4). Thus, the Moore Pediatric Surgical Center and Hermano Pedro Obras Sociales tended to work more with peri-urban populations and Partner for Surgery, rural ones.

Safety was a noted concern at the Moore Pediatric Surgical Center: The facility was located on the border of a city zone known for gangs and drugs, and, for example, a bakery nearby closed down when the proprietor decided she could (or would) not pay extortion fees. Despite flyers and print advertisements noting the clinic's address, no other confirmation of what lay behind the blue-painted façade was posted on-site.

Table 2: Recruitment of parents/guardians and healthcare providers from clinical sites/NGOs.

Clinical Site/NGO	Parents/guardians (n = 29)	Healthcare providers (n = 8)
Moore Pediatric Surgical Center	27	2
Hermano Pedro Obras Sociales	2	0
Partner for Surgery	0	5
Other †	0	1

† Fundación Ayúdame a Vivir, a foundation that works with the Guatemalan Ministry of Health and Welfare to treat pediatric cancers.

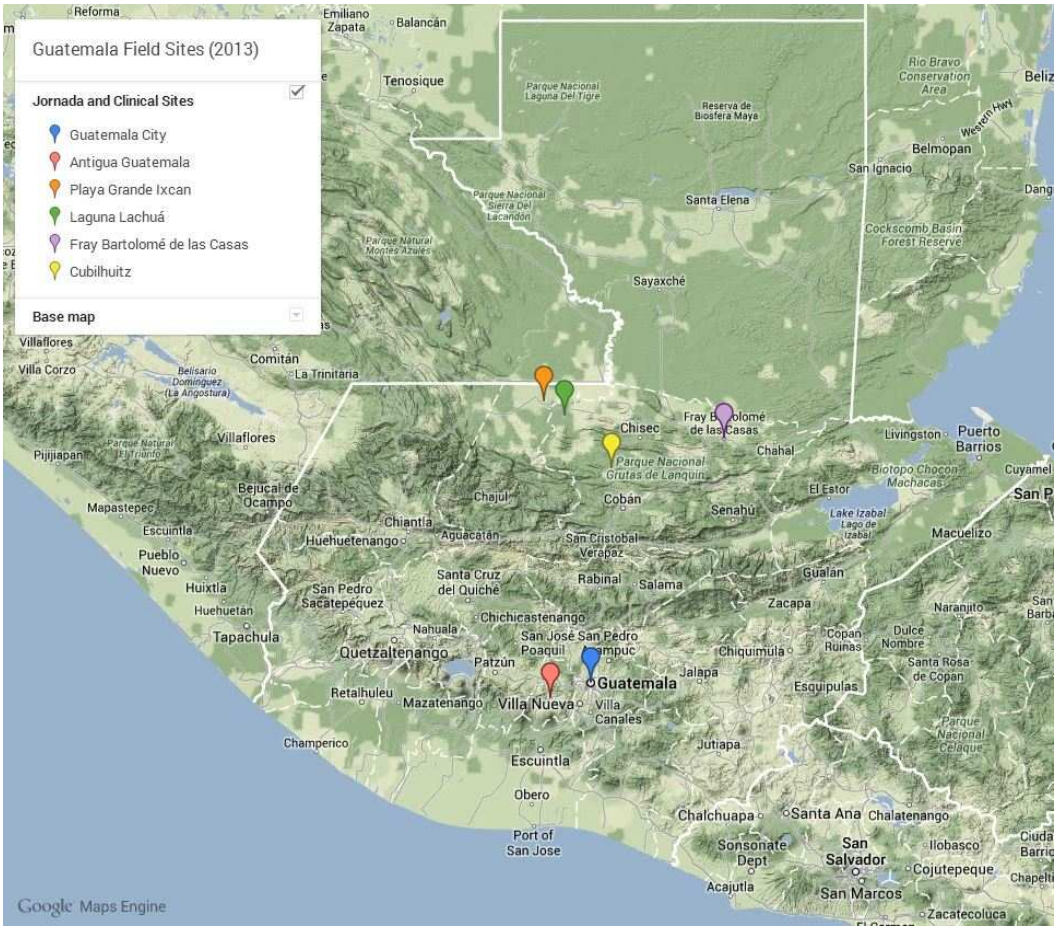


Figure 4: Jornada and clinical sites during field work in Guatemala.

2.2 Interview Procedure

Over a 10 week period from June to August 2013, we conducted semi-structured oral interviews with twenty-nine parents/guardians and seven healthcare providers regarding their views of and experience with pediatric surgical care delivered by an NGO in Guatemala. An additional eighth healthcare provider participated by using the interview tool as a survey instrument, providing written responses in English. Two distinct study instruments were developed for families and healthcare providers (Appendices A and B). All family interviews were performed in Spanish in a clinical setting. The instrument for families was translated and back-translated into Spanish to confirm linguistic accuracy and cultural relevance. Six provider interviews were performed in English and one was conducted in Spanish. Notes taken during the interviews, supplemented and corrected by audio recordings, were drafted into interview transcripts and, if originally in Spanish, translated into English for analysis. Sampling was continued until saturation was reached (i.e., no new data was revealed) [CHEN 2009].

To confirm their language, feasibility, and fidelity, both interview tools were pilot-tested in a series of interviews with 3 providers and 4 parents. Subsequently, questions that had been found to be ambiguous or confusing were rephrased by the study personnel, though data from the pilot interviews were included in the analysis.

2.3 Sampling of Parents/Guardians

Twenty-nine Guatemalan parents/guardians of children receiving surgical care through an NGO were recruited via convenience sampling, having been invited to participate by a clinic social worker or health promoter. As three families had multiple children receiving surgical care, a total of 32 children were considered. These children received various types of pediatric general surgery, plastic surgery, urology, or otolaryngology procedures. Two children underwent multiple procedures under the same anesthetic, yielding 34 total procedures, as identified by their parent/guardian (Table 3). Ten interviews with parents/guardians were classified as "post-op," with two children having had surgery approximately 8 months prior to the interview, and eight children having had surgery approximately one week prior to the interview. Of the other nineteen families, nine were interviewed while the child was in surgery or immediately afterwards, and the remaining ten during their pre-op evaluation.

Table 3: Surgical procedures performed on children of parents/guardians interviewed for this study.

Surgery	# (n = 34)
Removal of tonsils and adenoids	11
Inguinal hernia repair	6
Cleft lip/palate repair	4
Reconstruction of pinna	3
Tympanoplasty	2
Orchiopexy	2
Excision of lipoma	1
Excision of breast mass	1
Correction of polydactyly	1
Repair of ear fistula	1
Unclear	2

2.4 Sampling of Healthcare Providers

A total of 8 healthcare providers were recruited: 7 participated in semi-structured interviews and 1 used the interview tool as a survey. Five providers, 3 Americans and 2 Guatemalans, were selected via convenience sampling from 2 NGOs in Guatemala: 1 at the Moore Pediatric Surgical Center and 4 at Partner for Surgery. Three additional Guatemalan healthcare providers were accessed via snowball sampling – asking a previous informant if he or she knows of other potential study participants. All providers spent at least a portion of their time providing medical or surgical care with these NGOs or organizations, and all providers had provided direct patient care within the preceding 2 weeks, minimizing recall bias. None of the providers who participated were directly involved with the development of this project.

2.5 Methodological Theory

Qualitative research methods were selected for this study for several reasons. First, this project builds upon the quantitative data on barriers to pediatric surgical care recently obtained via surveys at the Moore Pediatric Surgical Center [NGUYEN 2013]. Secondly, it contributes to the literature on barriers to surgical care more generally, in which there are only 52 qualitative research studies across all LMICs [GRIMES 2011, IRFAN 2012]. Thirdly, semi-structured interviews allow some sense of non-verbal response to questions and also the opportunity to probe or clarify responses. They also allow more freedom: Participants may not be limited to a set of ideas defined by

researchers. To be sure, exploration of unique cultural issues that had not previously been identified was one of the objectives of this project. Though certain issues may not be broached due to cultural norms (e.g., gender roles), taboo, or embarrassment, what is not said may also be as important as what is. Lastly, semi-structured interviews also allow participants to suggest the relative importance of particular perceived barriers to one another. In this particular study, interviewing both parents/guardians and healthcare providers allowed insight into what each group witnessed and prioritized.

As with other studies using in-depth or semi-structured interviews [CRONIN 2008, BROCKINGTON 2013], we used grounded theory to analyze the data [CORBIN 1990, SCOTT 1999, WALKER 2006, CHARMAZ 2008, CHEN 2009]. Ann Cronin explains this iterative process: "The researcher typically begins by examining the data line by line, identifying themes and coding these, then developing these codings to capture multiple meanings, coding convergence and divergence, and the relationship of codes to broader categories" [CRONIN 2008]. Put another way, the grounded theory method "is concerned with generating and suggesting categories, properties, and hypotheses about general phenomena," letting the data determine these categories [CHEN 2009]. Initially developed by Barney Glaser and Anselm Strauss (1967), grounded theory attempts to "integrate the strengths inherent in quantitative methods with qualitative approaches" [WALKER 2006]. Though a methodological split eventually arose between Glaser and Strauss – "whether the researcher uses a well-defined 'coding paradigm' and always

looks systematically for 'causal conditions' [KELLE 2005] – grounded theory has both systematic ("scientific") and creative ("artistic") elements [WALKER 2006].

2.6 Codebook

Using the organizational and analytical approach described above, a unique codebook was created: After all interviews were completed, we reviewed each transcript, identifying recurrent themes and drafting them into 16 parent (root) codes (Appendix C). One code – education – featured only demographic data and is not presented here individually. Child and grandchild codes, specifying certain aspects of the parent codes, allowed for better organization of raw data.

Each interview was then reviewed again, using this codebook template, with all references to these themes recorded. For example, citations regarding gratitude or the cost of transportation were collated under the appropriate heading in the codebook. Direct quotes from interviewees and paraphrased comments considered relevant to each code were taken directly from the transcripts.

An inventory of specific, individual barriers (e.g., fear of anesthesia) was created and the relative frequency of each concern was noted. These items were then initially classified as belonging to 1 of 4 larger domains described by Irfan's Healthcare Barrier Model (HCB) – patient, provider, health systems, and environmental issues – though some overlapped multiple areas and others were hard to clearly assign [IRFAN 2012]. Similar barriers were grouped together, yielding a shorter list of 6 general types of

barriers: financial and opportunity costs, systems limitations, mistrust and fear, health literacy and education, geography, and cultural issues. To test the appropriateness of using Irfan's model, these genres were then mapped back to test for fit. Analysis was not computer-assisted.

2.7 Ethics

The Duke University Institutional Review Board (IRB) approved this study. Medical providers and patients' families were enrolled in this study after reviewing the risks and benefits with the interviewer and having an opportunity to ask questions. Consent was documented with a signature in all but one case, in which an illiterate study subject gave witnessed verbal consent instead. Audio recordings, if obtained, were permitted first by the interviewee. Participants in this study did not receive monetary or in-kind compensation, nor did their medical care change in any way.

3. Results

3.1 Demographics

All 29 parent/guardian interviews were with the child's adult family member. Demographic information on gender/relationship, rural/urban residence, languages spoken, and education was collected (Table 4). Of the 8 caregivers who reported a rural residence, 6 (75%) thought they lived far from the clinical site, and of the 21 reporting an urban/suburban residence, 8 (38%) thought the distance was far, a descriptor not defined explicitly by the interview instrument or parent/guardian. Indigenous identity was not asked directly but implied through language fluency. Parents/guardians had an average of 9.9 years of formal education, though none of them mentioned informal education (e.g., on-the-job training, life experience). Including children and extended family, the mean household size was 6.1. The 32 children ranged in age from 15 months to 18 years (mean 6.8 years, standard deviation 4.3 years), and they were evenly split between male and female genders (i.e., 16 each). Family interviews ranged from 10 to 31 minutes, with an average length of 17 minutes.

Table 4: Demographic information for parents/guardians interviewed in this study.

Parent/guardian demographics	# (n = 29)
Gender/relationship	
Mother	19 (66%)
Father	8
Aunt	1
Older sister	1
Residence	
Urban/suburban	21 (72%)
Rural	8
Language(s) spoken	
Spanish only	23 (79%)
Spanish and a Maya language	
Kaqchikel	2
Kiché	1
Mam	1
Ixil	1
Achi	1
Education	
Illiterate	1
Primary	
1a-3a primeria (1st-3rd grade)	3
4a-6a primeria (4th-6th grade)	7 (24%)
Secondary	
Basico 1-3 (7th-9th grade)	4
Tertiary	
Diversificado (general high school)	2
Bachiller (similar to diversificado)	2
Preterito contor (training to be an accountant)	3
Majestario (training to be a teacher)	1
Licenciatura (Bachelor's degree)	5
Maestrado (Master's degree)	0
Doctorado (Doctorate degree)	1

Demographic information on the 8 providers' gender, nationality, ethnic/cultural identity, and medical training was also collected (Table 5). Providers' ages ranged from 29 to 67 years, with a mean age of 51.4 years. Providers had an average of 18.4 years of

post-graduate experience (range: 10 months to 30 years), and 2 were the medical directors for their respective NGO. Estimates of time spent providing care in medical/surgical missions were difficult to compare between providers, as some providers indicated just the number of trips taken, and others, the number of years spent with the particular NGO or hospital. Provider interviews ranged from 19 to 53 minutes, with an average length of 33 minutes.

Table 5: Demographic information for healthcare providers interviewed in this study.

Healthcare provider demographics	# (n = 8)
Gender	
Male	5 (63%)
Female	3
Nationality	
Guatemalan	5 (63%)
American	3
Ethnic/cultural identity	
Non-ladino/ladina	3 (38%)
Ladino/ladina	3
Mixed	2
Terminal degree	
Doctor of Medicine (MD)	7 (88%)
Advanced Practice Registered Nurse (APRN)	1
Specialized training	
Family medicine	4 (50%)
Pediatric primary care	1
Pediatric surgery	3

3.2 Codebook Themes

3.2.1 Surgical Conditions

Five providers indicated that less than 5% of the patients they referred within or saw in the NGO system had emergent problems. Six providers, however, reported the surgical concerns they addressed were urgent. Stated the medical director of one of the NGOs,

> "We just attend elective surgeries, but sometimes the patient has been waiting so long, at the moment we see them, the patient needs the surgery soon."

She further indicated that her focus was on improving lives, but that the national hospitals attended to those who were at risk of losing them.

One provider noted that it is more common to see complex congenital problems in the national hospital and more simple operations (e.g., hernias, orchiopexy, circumcision, appendectomies) in private practice. Four providers mentioned limitations with being able to access specialty care in oncology, orthopedics, neurosurgery, cardiac surgery, or transplant surgery. This appears to have been due to lack of qualified surgeons, the complexity of surgery, and/or the need for follow-up care.

3.2.2 Costs

In general, money was considered to be a very important factor limiting surgical access by both families and by providers. Eleven families (38%) listed financial concerns as the biggest obstacle and/or that they were primarily driven to this NGO because care

was free. Although she took pride in the quality of the clinical site, one of the medical directors worried this could intimidate some families:

> "And then, when they come and see our facility, a concern of theirs is how much it will cost. Because it's a nice facility and the person treats [them] nicely but that is expensive [in] their minds because it looks like private services."

She also reported that social workers help families budget for surgery, using this investment to underscore the importance of health:

> "We are trying to teach our population that health is important and is needed, so we ask them to pay for their diagnostic labs, imaging, [etc.]. But if they don't have money, we will pay for them..."

One mother stated that even if she was not able to get money to cover the various costs, the NGO still would have operated on her son, whereas in other places, if she did not have money, they would not help her.

Generally, families stayed overnight at the NGO's clinical facility post-operatively. Some families who were still in the pre-operative phase were not sure if they would need to stay (e.g., "I don't know – no one has told me yet"), basing their expectations on past experiences.

Even though the NGOs provided surgery and medications free-of-charge or at reduced cost, families stated that they were responsible for expenses such as transportation, food, and diagnostic testing (Table 6). NGOs varied though, with some providing transportation but requesting a "donation" for the surgery. No families

mentioned paying in-kind, though some of the clinical staff did report this was sometimes done, using provisions of food or time spent volunteering.

Table 6: Relative frequency of mention of various costs incurred in the pursuit of pediatric surgery.

Mention of particular costs by parents/guardians	#
Transportation	(n = 29) †
Self-pay	20
Spouse paid	4
Other (NGO or other third party paid)	3
Not applicable (no cost incurred)	1
Did not specify	1
Reported cost: 10-300 Q ($1.25-40 USD) ‡	3
Food	(n = 14)
Family's responsibility	3
NGO paid for snacks only	5
NGO provided unspecified help	6
Reported cost: 100 Q ($13 USD)	1
Lodging	(n = 22)
Family's responsibility	6
"I will pay if needed"	3
NGO will pay	11
Part of "voluntary contribution" to NGO	2
Reported cost: 5 Q ($0.75 USD), 200-300 Q ($26-40 USD)	2
Laboratory and other diagnostics	(n = 29)
Family's responsibility	13
Not sure if laboratory tests needed	4
Denied or did not mention if laboratory tests needed	12
Reported cost: 30-230 Q ($4-31 USD)	10
Surgical care itself	(n = 12)
Family asked to make a "donation" to NGO	12
Reported cost: 75-500 Q ($9.5-63 USD)	5

† This number refers to how many parents/guardians, out of the total 29 interviewed, mentioned monetary cost and/or party responsible for payment for this particular item.
‡ Range of costs reported, and how many interviewees mentioned a specific value.

No families mentioned the cost of follow-up nor opportunity cost of being away from home (e.g., missed work, taking care of other relatives or children), though 4 of the healthcare providers did express the latter concern on the behalf of their patients.

3.2.3 Access to Health Services

Parents/guardians generally expressed strong concerns about their limited ability to access public or private surgical services. Families reported that they learned where to seek care from newspaper ads placed by the NGO [n=9], by referral/suggestion of local providers [n=8], other NGOs or other social contacts [n=3, each], or radio or television ads or bulletin board flyers [n=2, each]. One family member specifically reported that it was the radio broadcast of an interview with a previous patient at the NGO that gained his confidence.

Four families stated that financial limitations were a reason they sought care from the NGOs rather than public or private facilities, with long waits or inability to get an appointment [n=2], frustration with inefficient medication regimens [n=2], and conflicting information [n=1] noted. Several families reported having been to 3 or 4 other providers or facilities prior to accessing an NGO for definitive surgery. Three families reported persistence in seeking care despite treatment failures – for instance, one family knew their daughter needed cleft lip surgery since birth, but had to wait 1.5 years for the child to be old/large enough. When that surgery failed, she had to wait another 1.5 years before reconstructive treatment was provided. Another family reported 11 years' worth

of recurrent ear infections before the child received surgical care. Twelve families had only been to public facilities; 4 had only been to private facilities; 4 had been to a both public and private; 6 did not specify whether previous providers worked in the public or private domain; 1 received care from another NGO; and 1 had not sought care anywhere else first.

Fourteen families thought that they lived far away from the clinical site. However, what some deemed as far (e.g., an hour) was not that way for others. Twenty-two parents/guardians provided an estimate of total transit time to the clinical site, ranging from 30 minutes to 5 hours, with an average time of nearly 2 hours. One participant who reported living 2 hours away still described this as "pretty close." Means of transportation included bus [n=25], truck [n=2], private car [n=5], motorcycle [n=1], and walking [n=2], with families sometimes using a combination of modes, multiple vehicles within a particular category, or different methods on different trips. One mother reported the concern of transit violence en route, and another reported that having to be at the clinic at 6am might mean having to find a place to stay in the city the night before.

Sixteen families reported having laboratory testing and/or radiographs. Of these tests, plain x-rays were the most common [n=7]; followed by blood, urine, and stool samples [n=5], and unspecified labs [n=4]. Unspecified blood tests [n=1] and diagnostics

in general [n=3] were also mentioned. More specialized tests included blood coagulation tests [n=1], a head CT [n=1], and acoustic brain resonance [n=1].

Healthcare providers confirmed widespread concern about access to surgical services. Several providers recognized that coming from a rural environment made access to care more difficult. Said one healthcare provider,

> "In Guatemala, it depends where you live. Everything is centralized in Guatemala City."

The medical director of one of the NGOs reported that approximately 50% of the families live in or near Guatemala City, with the other portion "far away" from it.

One Guatemalan provider reported national hospitals only seemed to reach out to the local community, rather than being available for families outside of local areas. Another provider cited that although Guatemalans were supposed to have federal access for healthcare, it did not allow appropriate access to care. The medical director of one of the NGOs stated her organization caters to those who "are in need and don't have the resources," and a surgeon noted surgical missions in the field allowed her access for "patients that otherwise I probably wouldn't have the chance to treat."

Providers noted many patients had previously sought care at other public or private clinics and came to them if the treatment failed to produce results or if the family or patient wished for a second opinion.

Once aligned with an NGO, families generally were required to have further pre-operative workup, which posed additional challenges. One American provider expressed concern with the amount of required testing by the NGO:

> "I'm afraid that quite often the tests are done and nothing is being done as a result of that test being done."

None of the parents/guardians reported seeing "traditional" providers such as herbalists or bone-setters for surgical care for their children, though four healthcare providers reported patients will sometimes pursue this route of care. One pediatric surgeon expressed particular concern for this modality, having seen serious complications from delays in definitive surgical care.

3.2.4 Expectations of Surgery

Healthcare providers stated some of their patients had unrealistic expectations of what conditions needed or would benefit from surgery, what could be done and when it would occur, but none of the families reported being surprised by these limitations.

With such high expectations, it was sometimes hard for families to accept what the providers could offer, said one medical director, but also hard for providers to offer what families would want to accept.

Per the providers, patients had to progress from triage to the operating room in a reasonable timeframe or else the patients would either develop mistrust of the institution or fail to follow up entirely. Families were unaware that certain condition

needed to be treated through multiple, separate procedures. Similarly, some patients mistakenly believed they'd have their surgery on the same day they were screened.

3.2.5 Experience with Surgery

Families' experiences with surgery can be broken into 3 phases: pre-operative, the operation itself, and recovery. Nine families stated they had known "since birth" that surgery was needed. Other families noted an extended period of assessment and diagnosis before a decision was made for surgery. This interval caused them frustration, being "bounced around" from provider to provider and waiting 3-6 months between each of these referrals. One mother reported her son suffered through 11 years of repeated ear infections and doctors' appointments before he was identified as a surgical candidate for correction of his problem.

Once families knew that surgery was needed, however, it was not uncommon for families to wait several years until they received surgery. Of the 18 families in our cohort who were in the peri- or post-operative period, 50% waited 3 years or more for surgery, with two families stating they waited 6 years. In contrast, three families waited 6 months or less. One mother stated this period was lengthened because she did not have the money for surgery, and other parents noted it was because the child was sick on his or her surgical date and had to be rescheduled. Another mother stated that trying to keep delays to a minimum was important. She sought care from this particular NGO because another site would only schedule surgery for the coming year and "[she] couldn't wait."

None of the families reported a preference for a particular type of healthcare provider in terms of age, gender, nationality, or ethnicity.

Of the 12 families who had been discharged from the hospital at the time of the interview, all stated they followed post-op instructions and were able to give specific examples (e.g., decrease physical activity, take prescribed medications, eat soft or cold foods).

One of the medical directors speculated that delays in care inspired skepticism: Families often didn't believe her when she advised them her scheduling coordinators would call them back to make an appointment. Nonetheless, other families were persistent, even when counseled that surgery was not necessary:

> "If they're told by someone they respect that the kid needs surgery, it doesn't matter what the surgeon said. They're looking for someone that will do it."

Providers were also concerned that numerous doctors' visits and tests could result in wasted efforts – such as providing a requisition for an EKG that a patient had already had or couldn't afford. Said one of the American providers:

> "So they may have a worthless piece of paper they carry around with them until the next team comes."

Even if the diagnostic test is completed, "who's following up after that's done?"

In terms of post-operative experiences, half of the providers reported they had had problems with families failing to adhere to their instructions (e.g., regarding wound care, diet, medications, and/or activity restrictions). One of the medical directors noted

that despite frequent repetition in verbal and written (or pictorial) forms, many families still failed to follow their care plan.

Some families did not understand why they had to remain hospitalized after surgery. One surgeon noted that the type of treatment she provides "demands time for rehabilitation and [the patients and/or their families] just want to come home after surgery. It is difficult to make them understand." For older patients and parents, guarding one's own social or physical capital was important. Said one of the medical directors,

> "Most of them do heavy physical work, so it's hard for them to be away from work… [and] they probably go back before it's time."

Another surgeon noted that in his private practice, he would sometimes truncate post-operative hospital stays for this reason, starting to feed patients earlier than practice standards might indicate, for example, or starting rehabilitation early.

Although one of the medical directors indicated that she tried to have the same surgeon follow the child post-operatively, scheduled follow-up care was not always possible. Some NGOs and national hospitals lacked this capacity in their own facilities and instead counsel patients to visit local providers, relying on local health promoters to relay concerns to the NGO. Said one medical director, whose NGO works in communities all over Guatemala,

> "Most people, when they leave, they leave. They only call you when they are concerned. We don't have the capability to do follow-up across the board…"

3.2.6 Provider Experience of Surgical Missions

With regard to provider experience, American providers generally focused on protocols that helped them with triaging patients, but Guatemalan providers didn't reveal a common theme. Two of three of the American primary care providers mentioned being provided with guidelines to help them with triaging patients. Said one,

> "We have a sort of a sheet that says this is the type of surgical team that is likely to come and the problems that they can efficiently take care of that don't require a lot of post-operative intensive care."

This provider wished for "accurate feedback on whether the referral was appropriate and the outcome of the surgery." Another one of the American providers felt challenged by the lack of resources and communication, being unable to obtain particular diagnostic testing or to discuss the management plan with the surgeon. One of the Guatemalan providers echoed this sentiment with regard to follow-up, having to send patients to a rural health post or community health center because he was unable to have a surgeon reevaluate the patient in his or her own community.

Most NGOs attempted to continue communication with volunteer providers, and one of the American providers did comment on the teamwork within the mission groups. Life in the field was fatiguing, due to the volume of patients and environmental conditions. Working in the hospitals was challenging for Guatemalan staff as well due to balancing the financial concerns of the provider with the needs of the patients:

> "At [a national hospital], I get paid by the government. I get paid for 4 hours... but a lot of the time, I stay there longer... My main income comes from private

practice. If I really have to cover my expenses and everything, the house, school for my kids, foods [sic], everything, I need to do private practice."

3.2.7 Services and Volume of Patients

Providers tended to view the population they served as poor and poorly educated. Though some supportive programs were mentioned, most providers noted a general lack of health care resources such as manpower. Two American primary care providers and one Guatemalan surgeon commented on the daunting number of patients that presented for triage. Six providers shared their perceptions of these patients, describing them as poor [n=6], less educated or having limited health literacy [n=5], rural or isolated [n=3], indigenous [n=2], and with language barriers [n=2]. One Guatemalan surgeon suggested a causal pattern:

> "And because of lack of education, they have many children. And the more children, the fewer opportunities there are to pursue studies. Meanwhile, less education, more need. And less opportunities [sic]."

Primary care providers provided a small volume of minor procedures in the field but their main task was to "decide which [patients] fit the surgical teams coming down and try to get them in shape medically." To help with this, infant nutrition programs – as mentioned by 3 of the primary care providers – helped malnourished surgical candidates gain weight in the period before surgery. This longitudinal effort was thought to inspire trust in families, "so we can assure the patient will come for the surgery." Most procedures were attempted in the operating room, particularly by general or plastic surgeons. Whereas one Guatemalan surgeon reported there was no

difference between (caring for patients in) the national and private hospitals, one of the Guatemalan medical directors lamented,

> "The years I worked with the national hospital, I didn't like to work there... You can see a patient but you didn't have the resources to help."

3.2.8 Resources for Providers

Limited local manpower and support services were common themes among most providers. Three providers – two primary care providers and one surgeon – noted the importance of having appropriate clinical facilities near to the patients, including allied services such as radiography/ultrasonography. One of the medical directors reported that social workers help families budget for surgery, using this investment to underscore the importance of health:

> "We are trying to teach our population that health is important and is needed, so we ask them to pay for their diagnostic labs, imaging, [etc.]. But if they don't have money, we will pay for them..."

Three providers discussed how health promoters improved the delivery of care:

> "The reason we can do what we do is our promoters... They usually live in the same place that the patients do, so they share their own culture, they share their own language, and they are able to transmit the message we are trying to get to them."

3.2.9 Perceptions of Quality of Care

In assessing quality of care, parents/guardians seemed to rely more on subjective measures, and healthcare providers, on objective measures. All 29 families reported they received good care from the doctors and nurses. Collaboration between specialists,

completeness of services, commitment to care, and compassion were the overall themes expressed. Staff members were described as friendly, nice, caring, and attentive. "It's better than if I paid 8000 Q [~$1000 USD] at another place," said one mother. "You can see the love that the staff has [sic] here." Families either cited good surgical outcomes (e.g., "in a short time, he was improved greatly and the recuperation was quick") or specific gestures of generosity (e.g., provision of a piece of bread as a snack) as the proof of these sentiments. The cleanliness of the facility was also mentioned.

Healthcare providers expressed interest in workers' credentials ("the somewhat unknown quality of the volunteer triage and/or surgical MDs" and "the problem with developed world doctors being unfamiliar with many of the diseases and conditions of the developing world"), technical skill, and low rates of complications (e.g., wound dehiscence, surgical site infections).

3.2.10 Patient Confidence

Trust in providers and health care institutions (or lack thereof), religious faith, and fear of the unknown shaped parents/guardians' confidence throughout their experience seeking surgical care. Perceived differences between Guatemalan and foreign providers were a point of contention among several families. Twelve parents/guardians reported having more confidence in foreign providers. When asked if they would have preferred to have a Guatemalan provider rather than a non-national, 17 respondents

said they would not. These families seemed to be more appreciative of the foreign providers, assuming more philanthropic motives. Said the mother of one patient,

> "They [foreign doctors] come here to cure and help people. Here in Guatemala, if you don't have money, they don't do it [the surgery]. But here [at the NGO], they come to help."

Foreign providers were also viewed as more professional and experienced and having access to advanced technology. Nine families, however, stated that it wasn't important to them whether they had a Guatemalan or foreign provider. Of these, two families said the choice was really up to God or Jesus, and two indicated they didn't have a preference, as it was the outcome – surgical treatment – that was important. Similarly, one mother noted it wasn't the nationality of the provider that mattered at all, but the organization that was orchestrating the surgery.

Thirteen families made reference to religion, with seven stating they were grateful to God, ostensibly for allowing them to find surgical care. The symbolic image and concept of being in another's hands was repeated, and 2 mothers implied fatalism by suggesting other families should "leave it in the hands of God." Though one of the medical directors said birth defects could sometimes be viewed, conversely, as a curse from God, none of the families endorsed this.

Despite this expression of religious faith, 8 families reported that uncertainty or fear of the unknown was the hardest part of their experience. Some tried to make a distinction between being scared and being worried. For instance, one mother stated

that though the prospect of having her daughter go under anesthesia was scary, she felt better about it after taking with the doctor. Anesthesia was a concern for six of the families; surgery itself, for only two; and post-operative complications, just one. In speaking for their children, two parents expressed a fear of pain, and one was worried her son would die as a result of the operation. In contrast, seven families specifically denied any worries.

One mother recounted the horror story of her daughter waking up before the surgeons had finished suturing the wound:

> "Well, [they told me] after the doctors had already left. So the nurse who'd been on shift that night told me what had happened with my little girl, and told me that she's woken up when they were still sewing her up. And so they [the doctors] didn't finish sewing her up well. That's why [her cleft lip opened back up]."

One of the Guatemalan providers acknowledged families might be scared about what would occur while their children were away in the operating room:

> "And then they are concerned that foreign people are coming, and some years ago there was a black market for organs, so one of their biggest concerns is that when the kid is asleep, what are they going to do to my kid? Are they going to take a kidney?"

More generally, providers speculated patients were worried about the unknown:

> "There are a lot of misconceptions around surgery… Everybody, in some sense, doesn't know exactly what's going to happen, so they don't know what to expect. Sometimes [the families] misunderstand the procedure. This happens a lot with cleft lip/palate, when they are going to need more than one surgery… and they think the first one failed."

One of the medical directors explained how her NGO earned families' and communities' trust: It worked with organizations that were already known and trusted in the community. Between this, the 6-8 month process of preparing for surgery (triage and medical workup), and having other community members who had already successfully received surgical care, families were able to put their trust in the NGO.

3.2.11 Health Literacy

Several parents/guardians did not understand the surgical procedure performed on their child. Although most family members were able to identify the general area or system affected, 7 out of 29 could not name the condition from which their child suffered. One participant stated this was because "no one told me."

Two of the providers commented on health literacy and education specifically – one, that families "may not understand whether they have a significant problem or not," and the other, that families "didn't know what they have or what to expect" and needed to be guided through the medical system.

3.2.12 Language

None of the families interviewed expressed concern over language. Of the providers, only the Americans commented on language barriers, particularly for the use of Maya languages. There were hints of self-doubt:

> "… Maybe I don't have enough of the language to discuss [patients' concerns] with them."

Though usually they had access to translators, one of the providers said,

> "There's always a concern that […] something gets lost in translation and they didn't get a good understanding of what's going to happen with the surgery."

Another advised,

> "I don't have a language barrier in my home community… I think the biggest problem for me is the language barrier. Especially when you have English to Spanish and Spanish to Q'eqchi'. I know that things get lost in there. Because just speaking English to English with my patients, they don't understand and hear everything you say to them. So I think the language barrier is a huge problem."

None of the American providers expressed concern over speaking Spanish, and none of the Guatemalan providers over Maya languages, though one of the medical directors suggested indigenous families themselves might be apprehensive:

> "With indigenous people, the concern is probably the mother will not speak Spanish so they will not be able to communicate."

3.2.13 Decision-Making

Healthcare providers observed that gender roles and community networks sometimes impacted care-seeking behavior, but this theme was not mentioned by families. Two providers observed that wives were sometimes hesitant to agree to a particular plan of care until they got permission from their husband or that men were reluctant to let their wives travel alone. Once this barrier was surmounted, however, the men were usually accepting of the surgeon's plan. Community members who had already had a particular surgical procedure inspired trust in others for the NGO and, more generally, instilled in them more confidence to go out and seek out needed care.

3.2.14 Monitoring and Evaluation

The American providers expressed frustration over lack of feedback, with one stating it was important "so I can learn." These providers weren't sure if their referrals had been correct, what the outcomes were, or what services were available for follow-up. Another stated that in the 8 years he had been volunteering, he had never been contacted by a surgeon about a patient he saw. Said the third provider,

> "Here [in Guatemala], they [the patients] kind of go into a no-man's-land after we see them because we never see them again and we hardly ever get any kind of feedback. It's kind of sporadic. We never talk to the surgeons."

The Guatemalan medical directors had different thoughts on quality improvement: One looked at "improving our medical service by learning from other teams," and the other, improving the culture of care:

> "I believe in focusing on quality – quality [care] and quality control… It's not only to take people to surgeries but to assure they get good treatment while they're getting surgery."

Emphasizing the importance of the health promoters, he stated that there were 3 principle parties in delivery of care – the patients, the NGO staff, and foreign providers – and trust is needed from all invested actors. A patient may share his/her good experience with a few people, but a bad one with many. Similarly, if a staff member or volunteer physician has a bad time, he or she will not want to continue working with the NGO. This care is a service, not a favor, he remarked.

3.2.15 How to Improve Care

Every single caregiver and provider made some kind of recommendation as to how care could be improved within the NGO and/or Guatemala in general or offered hypothetical advice to families pursuing pediatric surgical care. One mother thought more advertising should be done. Two fathers suggested it would be helpful to have the NGO in other locations in the country, "closer to home."

With regard to Guatemalan health care in general, families were frustrated, stating that attention in the public hospitals was poor and slow, treatment was sometimes inconsistent, and that care was only available if one could pay ("if you can't pay, then they don't help you"). All of this resulted in families having low confidence in care. Said one mother,

"They treat you like you're a nobody."

In comparison, in the NGOs,

"You feel good because everyone is equal [there]."

Experiences such as having to sleep in hallways or "outside under the trees," or purportedly being thrown out of the hospital less than 3 hours after surgery "because they needed the bed and we were to return home" were unnerving for families. Two caregivers expressed that lack of information in Guatemala was a problem, with one suggesting students should learn about common medical problems – as well as the jornadas – in school.

Said one mother,

> "Sometimes the parents do a lot to overcome obstacles, but it's not always enough and one needs to fight."

This sentiment of needing to be aggressive in pursuing care was echoed by 8 other families. Conversely, four families had more passive advice for others, two suggesting that one should have faith and two suggesting that one should have patience. Twenty families explicitly advised that others needing surgical should come to the same NGO that provided them care.

American providers mentioned more logistic improvements: "a stable site to do the surgery and one that's a little more accessible to the people in the remote areas of Guatemala" and crowd control and a limit to the number of hours spent seeing patients during jornadas. One Guatemalan surgeon wished the visiting medical teams were better organized:

> "Nobody knows they are coming… and if the plastic surgeons here knew, they would work with them and do some of the really tough cases."

One American provider also hoped for better coordination between the NGO and the Ministry of Health, as well as improvement in the Guatemalan healthcare system such that the NGO would no longer be needed. One Guatemalan surgeon suggested volunteer providers should "investigate the most important needs of healthcare of the country, the population, the traditional thinking, and [be able] to explain in detail what are the expectations of any treatment."

One of the Guatemalan surgeons thought the country's politicians should focus on education and health. His priorities in the health sector "would be to improve the infrastructure, the apparatus, [and] improve the power of the doctors." Another Guatemalan surgeon thought the number of medical facilities should be increased, making them more accessible to the population. Besides improving the facilities, he also thought the surgical training process could be improved: Board-certified surgeons were only in the hospitals for 4 hours a day – after that, it was just the residents. And for specialized surgical training, one often had to go out of the country. Upon returning to Guatemala, these providers wouldn't be able to pay back their loans if they only worked in public hospitals. A third Guatemalan surgeon thought the public hospitals should have better resources, "mainly supplies, [but] human resources also." Lastly, one of the medical directors, citing how most all medical care is centered in and around the capital, said,

> "The first thing is access. Millions of people don't have access to healthcare. That's the main issue… and even when patients are able to access a health post or health center, they usually have lousy treatment. Most health posts don't even have a doctor…"

Advice from healthcare providers was a bit more varied, with one American provider suggesting families bring as much information with them as possible (e.g., birth weights and follow-up weights, imaging reports) and one Guatemalan surgeon advising families should feed their children well, limit the number of children, and provide children with a good education:

> "The average girl doesn't attend more than 2 years of high school. Their parents need to believe their child can attend school. The average family has 5-6 children. It's terribly complicated for the children, who don't have opportunities. The common factor in this drama the people live is education."

Education may beget rights. One of the medical directors concluded,

> "The population needs to ask for their rights. Because what happens is everyone is in silence and no one says what their needs are. And then the government needs to put the attention on health services. We can't live in just healing but also preventing. And every doctor, nurse, and private practice provider needs to make a conscious decision that we are in what we are doing because every person deserves good health, but sometimes because we're looking for money to survive, we forget that."

3.3 "The Hardest Part"

For one of the last questions of the interview instrument, parents/guardians were directly asked what the most difficult part of their experience had been thus far, including recuperation, if applicable. Three respondents didn't offer an answer to this question and 4 gave multiple answers. Uncertainty and worries about surgical risk (e.g., safety, anesthesia, potential for scarring) were voiced as the most common concerns, followed by financial costs, waiting and delays in care, and travel (Table 7). The 2 parents who reported difficulty with adhering to medical instructions were referring to their children not wanting to rest and/or eat liquid foods.

Table 7: Parent/guardian perceptions of the hardest part of seeking pediatric surgical care.

"The hardest part"	# (n = 32) †
Worry/anxiety/uncertainty	10
Money/opportunity cost	8
Waiting/time	4
Travel/transportation	3
Following medical recommendations	2
Finding where to get surgery/resources	2
Reported no problems	3

† Three respondents did not answer this question; of the 26 who did, 4 endorsed 2 or 3 answers, giving n > 26.

3.4 Application of Healthcare Barriers (HCB) Model

The frequency of mention of particular barriers or concerns ("quantified" data) was initially organized by Irfan's Healthcare Barriers Model (Appendix D). Given the design of this study – interviews with the parents/guardians of pediatric surgical patients – the "patient" domain was expanded to include "families" [IRFAN 2012, ANDERSEN 1995]. Data were not organized therein by the predisposing, enabling, and need factors from the "population characteristics" portion of Andersen's behavioral model of (healthcare) utilization, however. Items that overlapped between domains were noted with a primary and secondary categorization: Use of triage guidelines was thought to be barrier for providers primarily but also reflected a limitation of the healthcare system, for instance, and the high volume of patients presenting for care was primarily a challenge in the system and secondarily for providers.

These data were then reviewed for themes; similar concepts were grouped together to yield 6 genres of barriers, excluding sample demographics and suggestions for how to improve delivery of care (Table 8). Delays in care, patient volumes, available resources, and uncertainty in where to obtain care were thought to be "systems limitations," for example, and gender roles and language barriers, "cultural barriers." As a test of robustness, these genres were then compared both to Irfan's model, revealing that not all themes could be mapped back easily, and, separately, to what parents/guardians reported to be the most difficult part of their experience.

Table 8: Major themes and supporting data from interviews with parents/guardians and healthcare provdiers.

Barrier, concern, or other factor	Codebook reference(s)
Sample demographics	
>2/3 female	3.1
Mostly urban/suburban	3.1
79% spoke only Spanish	3.1
52% had 9th grade education or less (average 9.9 years)	3.1
Financial barriers/opportunity costs	
38% cited costs as biggest concern	3.2.2
Costs: transport (most by bus) and labs/diagnostics (radiographs most common) mentioned most, then lodging and food	3.2.2
14% cited costs as why they sought NGO over public/private	3.2.2
Provided donation	3.2.2
Money/opportunity cost as hardest part	3.2.5
3/8 reported push to leave hospital to return to work	3.2.5

Systems limitations	
33% saw newspaper ad	3.2.3
41% been to public hospital only; 14% both public/private	3.2.3
Frustration with medication regimen	3.2.3
Delays in care (50% waited 3+ years, waiting/time as hardest part)	3.2.5
Redundant results	3.2.5
High volume	3.2.6, 3.2.7
Poor access (poor treatment, unable to reach)	3.2.14
Mistrust/fear	
Need to move through system quickly or would develop distrust	3.2.4
Offering acceptable solutions	3.2.4
No preference for provider gender/age/nationality/ethnicity	3.2.5
Trust in foreign providers	3.2.10
Fear of unknown	3.2.10
21% anesthesia as biggest operative concern	3.2.10
Religiosity	3.2.10
NGOs work because of health promoters	3.2.8, 3.2.10
Post-op community members inspire trust	3.2.13
Poor treatment in public system (e.g., sleeping outside)	3.2.14
Education/health literacy	
Poor compliance to instruction/not understanding why to stay in hospital	3.2.5
Providers viewed population as poor (6/8) and poorly-educated (5/8)	3.2.7
24% couldn't name condition	3.2.11
Education begets rights?	3.2.14
Geography	
48% lived "far" from clinical site	3.2.3
Centralization of services	3.2.3
Transportation as the hardest part	3.2.5
Cultural barriers	
No language concerns with families but Americans concerned (Maya)	3.2.12
Gender roles and decision-making	3.2.13
Suggestions	
Need for feedback/quality improvement (QI)	3.2.6
More advertising	3.2.15
Sites closer to home	3.2.15
Go to same NGO	3.2.15
Need logistic improvements	3.2.15

4. Discussion

Access to timely and quality surgical care is a challenge for many, and the problem is amplified in the developing world and, potentially, also among groups with weaker political voice such as cultural minorities and children. Though local health care policy is often insufficient due to lack of data regarding surgical burden and cost, surgeons the world over are increasingly being encouraged to serve as advocates of public health and chronicle this unmet need and the resources necessary to better access [LUBOGA 2009, SETHI 2013]. Nonetheless, specific obstacles stymie certain groups, and long lists of barriers published in the literature may not reflect the local context or suggest relative importance of these barriers and how they factor in to individual behavior. Qualitative study can help untangle these issues. Here we focused on pediatric patients receiving care from NGOs in Guatemala, as the impact of route to deliver care is unclear [OZGEDIZ 2009], and, with comparatively smaller patient volumes and better operating budgets, NGOs may be more willing and able than national facilities to adjust their methods based on new research.

Perceived barriers to pediatric surgical care provided by NGOs in Guatemala were enumerated both by asking parents/guardians directly what they found to be the most difficult part of their experience to be to date (Table 7) and through analysis of interview transcripts for themes (Table 8). The 6 major themes that emerged from the interviews – financial barriers/opportunity costs, systems limitations, mistrust/fear,

education/health literacy, geography, and cultural barriers – were similar to those revealed by the singular question to families. If anything, parents'/guardians' responses were more specific, with waiting/time thought to be a component of systems limitations, travel/transportation to be a question of geography, and following medical recommendations to be one of education/health literacy. Finding where to get surgery/resources could potentially reflect systems limitations or geography. As the two responses categorized under medical adherence were actually in reference to restricting a young boy's activity and diet post-operatively, the alignment with education/health literacy is spurious. Education/health literacy and potential cultural barriers such as language barriers or machismo were only ever mentioned by healthcare providers and so did not show up, in earnest, when questioning families. In other words, these 2 tables were not exactly equal but allowed for some triangulation of certain perceived barriers.

4.1 Critique of Sample

In this study, indigenous identity was assumed by using language as a proxy. In other words, parents/guardians who reported speaking a Maya language were thought to be indigenous or of mixed heritage, and those who did not, ladino/ladina (peninsular Hispanic heritage). Though this identity can also be discerned by self-report, cultural dress, or residence, it was thought asking this directly would be off-putting to participants. It is notable that all participants who spoke a Maya language also spoke Spanish.

The first thing to recognize about this sample of parents/guardians is that it represents a best case scenario, even though the families may not have felt privileged. In general, participants were ladino, Spanish-speaking, and relatively educated. That nearly one-third of families connected with NGOs after seeing a printed newspaper ad suggests a certain amount of literacy. The NGOs providing treatment to these families were also in fixed locations in nearby urban centers. Whereas the Moore Pediatric Surgical Center conducted multiple medical missions each year on-site for a variety of surgical specialties, Partner for Surgery made less frequent visits to more distant communities.

Though this sample obtained in this study is representative of the families seeking care the Moore Pediatric Surgical Center and Hermano Pedro Obras Sociales, it does not reflect the national composition, which is approximately 50% rural and 50% indigenous [WORLD BANK 2014]. Consequently, it is reasonable to assume that if these families reported facing a multitude of barriers themselves, those who faced racial discrimination, language barriers, poorer educational attainment, and further distances would have an even more difficult time accessing appropriate surgical care. Put another way, the families in this sample were likely in a better position at baseline to overcome expected barriers of finances, language, and distance. Being closer to centralized health services and potentially with higher-paying jobs suggests costs of transport and opportunities costs may have been lower than for other groups. Also, with an ostensibly

higher socioeconomic position, they may also have had more self-advocacy, as suggested by those who reported persistence in seeking treatment and encouraging other families to "fight [against the barriers]." The intrinsic methodological bias in this study of only interviewing those families who had at least reached the point of evaluation by an NGO implies the barriers they reported could be minimized if not circumvented entirely. Consequently, barriers to and delays in care were one in the same.

Nonetheless, there are subgroups in this sample that might show different patterns. The mother of the patient was the parent/guardian who participated for two-thirds of the interviews, but men and women may have had – or reported – different experiences. Similarly, comparison of those with more or less education, singular language fluency or polyglots, and urban/suburban or rural residence may reveal other nuances. Considering only demographics, for instance, there are some noteworthy details in this sample. Typically, indigenous Maya come from rural communities and receive less formal education. Here, none of the 6 parents/guardians who spoke a Maya language had greater than a 9th grade education, but only 1 of them reported coming from a rural location. Stratifying instead by this higher educational achievement, it is revealed that 4 of the 8 participants coming from a rural location, 5 of the 8 men, 7 of the 10 families in the post-operative phase of care, and 4 of the 9 families interviewed while their child was in surgery had greater than a 9th grade education. Though the sample

size is small, this suggests more educated parents might be more successful in obtaining surgery for their children, that men are slightly more educated, and that those in rural locations are actually no less likely to be educated. Similar analysis using gender reveals that only 2 male guardians came from rural communities but that 6 of the 8 fathers had a child in the post- or peri-operative phase. Of the families in the former phase, 50% of those interviewed were mothers and 50% were fathers, which overall does not suggest men were more successful in obtaining definitive surgical care for their children.

By comparison, one study on access to medicines for acute illness in middle-income countries in Central America showed that urban residence, higher education, having health insurance, and greater perceived severity of illness were some of the significant predictors of seeking health care. Successful access, on the other hand, was more likely for those seeking care inside the formal health system. Positive views of the public health sector, seeking care in the private sector, and higher education predicted full access there, whereas urban location, higher socioeconomic status, and male gender predicted access to care outside the formal health system [EMMERICK 2013].

4.2 Comparison of Families and Healthcare Providers

Though several perceived barriers were mentioned by both families and providers, there were multiple areas of disconnect. These are not purely differences between Americans and Guatemalans, as the populations each NGO served were slightly different. In this sample, 5 providers were affiliated with Partner for Surgery,

which tends to work in more rural environments than the NGOs from which the parents/guardians were sampled. Thus, families not included in this sample may nonetheless be given a voice by proxy. This may also explain the trend towards describing families as poor and poorly-educated the American providers' unique concern over Maya languages. What remains unclear is whether these concerns and generalizations were valid. Though they may simply reflect a population not directly captured in this sample, they may also reveal provider biases and weaknesses in cultural competency.

Health literacy – manifested in families' understanding of disease and adherence to post-operative instructions – was a key theme noted only by providers. That nearly one-fourth of parents/guardians couldn't name the condition from which their child(ren) suffered suggests failure on multiple levels, including education and communication. However, it takes a certain amount of understanding to appreciate the gaps in one's knowledge, and overemphasis on biomedical explanations and nomenclature may oversimplify issues of medical ethics, fail to respond to cultural beliefs, and, ultimately, blame the families for finding themselves in a vulnerable position. Even though providers reported families had poor compliance with post-operative instruction, this cannot be explained purely by the ability to read or understanding of medicine, as families were also subject to the opportunity costs of remaining out of work.

Whereas families in this sample generally only spoke to their singular, individual experience seeking surgical care, providers coalesced their experiences over various missions and in various sites, yielding a composite character that, though generalizable, may not capture more personal barriers.

4.3 Confirmation of Presupposed Barriers

Financial, systems, and geographic barriers can easily be identified in this study. These concerns were noted both when asking parents/guardians directly what had been the hardest aspect of seeking care and upon analyzing the interview transcripts for themes. Though the sample size is relatively small and some participants gave multiple answers, financial, systems, and geographic barriers ranked as the 2nd, 3rd, and 4th most difficult parts of families' experiences. They were also common themes elicited in interviews with both parents/guardians and healthcare providers. Thirty-eight percent of parents/guardians reported costs were their biggest concern and 14% cited costs as the reason why they sought care from an NGO rather than from a public or private facility. This confirms the findings from our previous quantitative research in this population, in which 50% of those surveyed found financial cost to be a barrier to surgical care [NGUYEN 2013]. Transportation and laboratory testing/diagnostics appeared to be the most salient extra costs for families, with 83% and 45% of parents/guardians reporting they'd be responsible for paying them, respectively. Additionally, not every respondent mentioned the cost of lodging or food, but of those

who did, 27% and 21%, respectively, expected to bear the cost. An additional 14% of families were uncertain if they would have to pay for lodging. Forty-one percent of families stated they had been asked to make a "donation" to the NGO for the care they had received. Identification of these potentially unplanned expenses – which reportedly ranged in value from the equivalent of $1.25 USD to $40 USD – is important for both families and NGOs as they coordinate a treatment plan and addresses one data gap in the literature.

Financial barriers do not affect just patients and their families. Opportunity costs represent another monetary dimension for families and providers and reflect the overlap and interplay of systems and contextual issues. Providers may receive less pay for more work in national hospitals, encouraging them to move to private facilities. Stated one surgeon,

> "At [a national hospital], I get paid by the government. I get paid for 4 hours... but a lot of the time, I stay there longer... My main income comes from private practice. If I really have to cover my expenses and everything, the house, school for my kids, foods [sic], everything, I need to do private practice."

With only about 5% of Guatemalans covered by private insurance [PAHO 2007] and only about 33% able to access care through the Guatemalan Social Security Institute (IGSS) [BOWSER 2011], most residents must rely on the public system. Families may neither be able to afford the price of insurance nor the time spent away from employment, waiting for care.

Public healthcare facilities in the developing world are often described as crowded and slow, with few resources and poor-quality treatment. Both parents/guardians and providers painted similar descriptions in Guatemala. Said one of the medical directors,

> "The first thing is access. Millions of people don't have access to healthcare. That's the main issue… and even when patients are able to access a health post or health center, they usually have lousy treatment. Most health posts don't even have a doctor…"

Reflecting on her experience in the public healthcare system, one mother complained,

> "They treat you like you're a nobody."

With over half of all families having sought care from at least one such clinic or hospital, the fact that these families still presented to an NGO for care implies dissatisfaction with or other barriers to accessing the national healthcare system (e.g., insufficient capacity). Families reported seeing multiple providers and specialists, receiving ineffective treatments (e.g., antibiotics) or conflicting information, and failing to receive return telephone calls. Even after knowing surgery was needed, some families reported waiting upwards of 6 years before receiving treatment. These multi-year delays in care warrant further exploration, particularly as it is unclear how NGOs may have contributed to or helped reduce these delays.

Healthcare services in Guatemala are mainly centralized in the capital city. Travel to Guatemala City is typically via twisting one or two lane roads that cross volcanic mountain ranges; traffic jams inside and outside city limits are common. Using

transit time as a proxy for distance, the average family in this study actually fell outside the defined parameter for having access to care – 1 hour or less [OWEN 2011] – with 2 families reporting their total travel time as 5 hours. Thus, even though 72% of families lived in urban/suburban communities and 52% thought they lived "near" the studied NGOs, linear distance only explains part of the geographic barriers.

These barriers are also well-documented in the literature. Whereas some organizational rubrics have granted financial, systems or geographic barriers their own domain, others have blended them among other categories (Table 9). For instance, though Carrillo et al. and Grimes et al. list financial barriers discretely, Scheppers et al. and Irfan et al. include it under (personal) enabling resources, a subcategory of patient-level factors [CARRILLO 2011, GRIMES 2011, SCHEPPERS 2006, IRFAN 2012]. Conversely, whereas these latter schema identify barriers associated with healthcare systems as one domain, these issues may blur across other groups in other frameworks.

Table 9: Comparison of classification of barriers.

	Scheppers (2006)	Grimes (2011)	Carrillo (2011)	Irfan (2012)	Kronfol (2012)
1. Origin	Literature review	Systematic literature review†	Evolving model and literature review	Systematic literature review ‡ (Pakistan)	Literature review (Arab countries)
2. Organization	Inventory (Andersen's behavior model of health services use as theoretical framework)	List	Healthcare access barriers model (HCAB)	Healthcare barrier model	Selected list
3. Categories	- Patient-level - Provider-level - System-level	- Social/cultural (acceptability) - Financial (affordability) - Structural (accessibility)	- Cognitive - Financial - Structural	- Patient - Provider - Health system - Environmental	- Geographic - Cultural - Organizational - Supply-side responsiveness - Financial
4. Application	Barriers for health services among ethnic minorities	Barriers to surgical care	Modifiable barriers to healthcare access	Barriers to healthcare in developing countries (surgical context)	Barriers to healthcare delivery

† Qualitative studies only.
‡ Developed from Andersen's behavioral model of health utilization.

4.4 Evaluation of Organizational Schema

There are a handful of published models, based on literature reviews, that attempt to organize perceived barriers to health care, though none of them are specific to surgical care or care delivered by an NGO. Irfan's Healthcare Barrier (HCB) Model is based on Andersen's well-established behavioral model of (healthcare) utilization [ANDERSEN 1995] and recognizes the interconnectedness of the various stakeholders: the patient, provider, health system, and environment [IRFAN 2012]. In contrast, Carrillo's Healthcare Access Barriers (HCAB) Model offers a different taxonomy –

financial, cognitive, and structural barriers – and focuses on what is mutable {CARRILLO 2011]. There exists some degree of subjectivity in what can be changed, however. Other models have instead considered the dimensions of access, delays in care, or health-seeking behavior [OBRIST 2007, THADDEUS 1994, HOCHBAUM 1958, STRETCHER 1997]. Sobo's phenomenologically-motivated model of parent experience in patient care traces a family's progression through the health care system, noting that deprivation, distrust, and failure to cure are potential outcomes [SOBO 2006]. As our current study is an exploration of barriers, irrespective of whether they can be minimized or overcome entirely, ascribing them to the main actors in this medical transaction more clearly defines the origin and effect.

Irfan's model, however, which was developed from research in Pakistan, focuses mainly on individual patient-level factors. Though this is the only model that is derived from a surgical context, there are a number of ways it is insufficient in organizing perceived barriers to surgical care in Guatemala. In trying to ascribe the major themes found in this study (Table 8) to the model, it becomes clear some modifications are needed to facilitate fit. First, rather than limiting discourse to the direct recipient of care ("patient level factors"), attention should be cast more generally to the family unit. This better allows for situations in which the patient is not the decision-maker (e.g., pediatric care, individuals without decision-making capacity) and may be more culturally-

appropriate in communities where decisions are made collectively rather than individually.

Second, financial concerns cut across multiple domains, including both direct costs to families and healthcare facilities and opportunity costs for families and providers to receive and provide care, as previously noted. The frequency with which this dominant theme is noted in this and other studies suggests it deserves specific attention, as it has in other models [CARRILLO 2011, GRIMES 2011].

Third, health care services are delivered differently around the world, and homogenization of these differences ("health system level factors") may make it difficult to pinpoint weaknesses or appreciate the interplay between sectors. In Guatemala, for instance, there are 3 sectors: the government-run public system, social security, and the private sector, which includes NGOs. It is important to clearly note where a perceived barrier lies, particularly when patients and their families move between sectors. Fifty-five percent of families in this study, for example, had been to a public hospital prior to seeking care at an NGO. Even though 50% of parents/guardians stated they had waited 3 or more years for surgical care once it was known it was needed, it is unclear in which sector(s) delays were most rampant. Similarly, though some healthcare providers disparaged the quality of care in the national system, they also commented on the volume of patients they saw while working with an NGO – two different types of barriers in two different sectors. Further, as NGOs often utilize short-term volunteers

and primarily attend to life-improving, rather than life-saving, treatments, their existence alters patient flow and may place burdens on other sectors (e.g., patients who have suffered complications with their NGO-based surgery may get relayed to the public sector for treatment).

Fourth, as these interactions take place within a particular milieu – an amalgam of geographic, social/cultural, and political factors – environmental-level factors could more clearly be rebranded simply as context [GAGE 2007, OWEN 2010]. The legal and migratory elements that Irfan notes in Pakistan did not emerge from this sample in Guatemala. Similarly, there was no mention of mistrust of government services due to recent conflict, and his model localizes culture – the set of social norms and practices – as a "predisposing patient-level factor" rather than a contextual one. Topography and terrain – and the costs of traversing it – are more important general aspects of the Guatemalan context, with transportation being a challenge and 48% of parents/guardians believing they lived "far" from the clinical site.

Fifth, worry/anxiety/uncertainty and health literacy are more nuanced obstacles centered in the family domain. They both relate to individual and family beliefs and knowledge, another "predisposing patient-level factor" in Irfan's model. This area deserves additional attention in the Guatemalan context, however, given both indigenous health beliefs and practices and the historical context of recent civil war. To be sure, families/guardians considered worries/uncertainty to be the most difficult part

of the care-seeking experience. Forty-one percent of parents/guardians reported having more confidence in foreign medical providers, whom they viewed as more philanthropic, more experienced, and with better access to more advanced technology. Conversely, 31% endorsed some fear of an event in the peri-operative period (i.e., anesthesia, surgery itself, or post-operative complications). Twenty-four percent of respondents couldn't name the condition from which their child suffered, and 25% of healthcare providers had concerns about families' health literacy. These cerebral elements reflect the core of surgical decision-making.

Thus, there are multiple aspects of this Guatemalan study sample that warrant modification of Irfan's HCB Model, which was developed for Pakistan: the pediatric patient population, the predominance of financial concerns as a major barrier, the focus on NGOs rather than the public health sector, centralization of health services, and both personal and greater community cultural barriers (i.e., beliefs and knowledge). This goes to show that aspects of other models are relevant (e.g., financial barriers, cognitive barriers) but no one model captures all concepts for this population. Consequently, the most important and accessible aspects from other published models – providers, systems, families, context, and financial – can be expanded and reimagined to yield the Framework for Barriers to Pediatric Surgery in Guatemala (FBPSG), depicted as a radial Venn diagram (Figure 5). In this schematic, the central star represents, with iterative

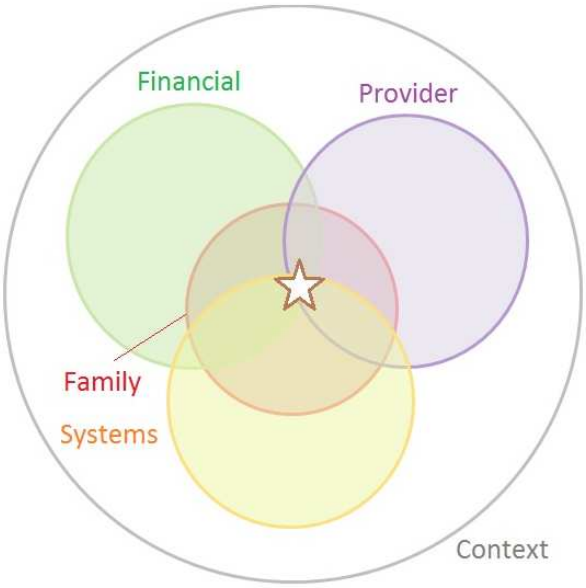


Figure 5: The theorized Framework for Barriers to Pediatric Surgery in Guatemala (FBPSG).

precision, individual cultural barriers, personal beliefs and knowledge, and fear and mistrust. This, too, is the heart of the hierarchy of resort, or process of health-seeking behavior. Overall, this framework might apply to other contexts, but as noted in meta-analyses that form a composite model, generalizations may not be possible from this specific visualization of pediatric surgical care delivered by NGOs in Guatemala.

4.5 Beliefs and Fears

What is novel about this study and the FBPSG is that fear and mistrust are not well-represented in other recent publications. It is tucked away in Irfan's and Carrillo's models. Hochbaum's Health Belief Model includes knowledge as a modifying factor but

focuses mainly on perceived severity of illness and perceived threat to well-being, rather than fears or explanatory models of disease [HOCHBAUM 1958, STRETCHER 1997].

Beliefs and knowledge come from experience, both formal and informal education, and include the central concept of trust. By offering an explanation for various phenomena, they can be a way of placating fears. It is unsurprising that parents/guardians endorsed fear of the unknown as they offered their child up for surgery, but this emotion serves as an entrée to a spectrum of trust. Said one mother,

> "I didn't know anything so I was scared [my son] might die."

The medical directors from NGOs spoke of trying to build trust and families reflected on what gave them misgivings. Examples of mistrust or lack of confidence in care included horror stories of personal or medical maltreatment: a child coming out of anesthesia before her procedure had been completed, with her mother only being informed later when complications arose; another child being kicked out of her bed in a national hospital because it was needed for another patient; and the lingering fear that a black market for organs may still exist. Said one father,

> "It's not the same with public and private institutions. They're very different. In the state institution… they operated on [my daughter] at 10:30am and at 1pm, we were thrown out of the hospital because they needed the bed and we were to return home…"

The latter instance also speaks to issues of the unknown: what goes on behind closed doors, the specific fear of anesthesia, and uncertainty with the details of diagnosis and treatment – another way of keeping families "in the dark," intentionally or otherwise.

Twenty-one percent of parents/guardians endorsed fear or worry over anesthesia. Said an older sister,

> "I have fear – I have never been through this before."

Long waits in public hospitals and a focus on payment before receipt of care lead parents/guardians to feel further disenfranchised, resulting in a mistrust of the system and suspicion of providers' motives. Consequently, non-Guatemalan volunteers were sometimes given elevated status – altruistic, experienced, and with advanced technology – a break from the norm and, like surgery itself, a potential remedy. Said one mother,

> "They [foreign doctors] come here to cure and help people. Here in Guatemala, if you don't have money, they don't do it [the surgery]. But here [at the NGO], they come to help."

Said an aunt,

> "Foreign doctors are more experienced and have better technology."

Nonetheless, providers, too, noted some details that reduced their confidence in the NGO's system: potentially uncoordinated efforts in the form of poor communication with surgeons and lack of feedback, repeated or futile testing requisitions, and lack of resources for follow-up. Said one of the American providers,

> "When we tell [the family] they need to get an EKG or ultrasound, first of all they've got to – I'm sure – pay for it, they gotta' get there, they gotta' pay for it, and then who's following up after that's done? Who's gunna' be there to read that ultrasound, or even act on it? So they may have a worthless piece of paper they carry around with them until the next team comes in."

In a study of cancer patients in Thailand, 52% reported a fear that they could not be treated or managed as a main barrier to accessing care. These patient-belief factors were associated with delay in obtaining care; socioeconomic status and systems limitations were not [BHOSAI 2011]. In other words, fears are one element that contribute to beliefs, which in themselves are cultural forces that may either be impediments to, or facilitators for, care. A sense of fatalism – such perceiving a cancer to be incurable or birth anomalies as being a curse from God – may lead to inaction.

Current organizational schema on barriers to care tend to focus on more "visible," palpable barriers and minimize the deeply personal, intimate issues of doubt and fear. These emotions are found on a spectrum of confidence, both in one's ability to confront barriers but also in providers' and systems' abilities to offer what is needed. Though "self-perceived disease status" and "perceptions, knowledge, and beliefs" are mentioned in Irfan's HCB Model, they can easily be overlooked. In Carrillo's HCAB Model, "cognitive" barriers are ambiguous and seem mainly to refer to education. These psychological elements are not considered from a purely biomedical approach, but they provide the filter through which the world is experienced. Previous behavioral models need to be merged with current barriers models so as to grasp the biopsychosocial factors that affect pursuit and receipt of surgical care. By annotating this central core with a star, the Framework for Barriers to Pediatric Surgery in Guatemala (FBPSG) draws attention to the individual and family unit and the beliefs that affect interaction

with all other domains. What is not named can more easily be dismissed, but this model attempts to provide space to understand it – a crucial feature when considering populations that have endured structural violence [FARMER 2004].

Though this organizational rubric considers the overlap of provider, healthcare systems, and financial factors on families and in a larger context, it carries the risk of becoming a dumping-ground for miscellany barriers, ones that do not fit clearly elsewhere. It does, however, attempt to keep from being too specific in listing barriers or over-grouping them.

In the Guatemalan context, mistrust or lack of confidence in existing systems is what is unique; worries about surgery are to be expected. This suggests NGOs need to work on garnering trust, not just providing physical access to care. By working with known, trusted individuals and organizations in targeted communities and by instilling the message that surgical care can be provided even to the poor, this is exactly what the medical directors of NGOs interviewed in this study reported trying to do. Thus, the FBPSG helps organize the factors that affect how people approach surgical decision-making and barriers within a Guatemalan, NGO-based context.

4.6 Engendering Trust

Nonetheless, there were ways in which the NGOs sought to earn the trust of families. With a staff mostly compromised of Guatemalans, NGOs may have a somewhat easier time assessing cultural needs than the visiting healthcare providers.

Gestures such as providing a family member a piece of bread were seen as evidence of compassionate care. Blurring the boundaries between systems limitations and fears and mistrust, but ultimately revealing how her anxiety had been eased, one mother said,

> "Waiting has been the hardest part. Because they [the children] go [into surgery] alone. But one thing I really like is that here they let someone go into the room with them [after the surgery]. In other national hospitals, they don't let anyone go in the room with them. So this way [in this NGO], you feel closer to them [the children]."

Said another,

> "As a mother, it's always scary to have your child go under anesthesia. But after taking with the doctors, I felt better about it and wasn't worried."

Working with organizations already in the community and recruiting/utilizing health promoters who lived there, developing rapport during nutrition programs and attempting continuity of care and follow-up, and instilling a kinder, gentler image were specific actions NGOs took to inspire trust. Said one of the medical directors,

> "The reason we can do what we do is our promoters... They usually live in the same place that the patients do, so they share their own culture, they share their own language, and they are able to transmit the message we are trying to get to them."

He added,

> "You need local people, local leaders, and if you go across them, and they [the leaders] say you can be trusted, they [the community] will trust you. In rural Guatemala, that makes all the difference."

With 69% of parents/guardians stating that their advice to a family in a similar position would be to come to this specific NGO, these efforts may have helped. Said one mother,

> "Everyone who enters [the NGO] gets great treatment until the last leaves."

One of the medical directors echoed this:

> "[Our main focus is] not only to take people to surgeries but to assure they get good treatment while they're getting surgery."

Shorter delays between steps in care, knowing a community member who had already gone through surgery, and, in the case of pediatric surgery, having a parent who spoke Spanish are other details that encourage compliance with surgical care in Guatemala [JACOBSEN 2010]. Said one of the visiting American physicians,

> "… They [the patients and families] tend to mistrust if there's a delay or a long delay, an unreasonable delay, so we try to avoid those kind of situations."

It is unclear, however, whether religion – particularly when it carries about it a sense of fatalism – acts as a barrier or facilitator to care. Said another medical director,

> "There are some types of surgeries that are easy to fill. But there are others like cleft lip/palate, burns, scar, or strabismus, that are very, very difficult to fill because they feel like it a curse from G-d, so they feel the child needs to stay that way. So they don't want the surgery… Or they leave the child to die because they think they [the child] don't [sic] deserve to live because they look like that. So those are every common challenges that we have to teach the people to, um, make them believe in us and come and prescreen."

Similarly, it cannot be determined whether referral to the NGO from another provider – as 8 families in this sample had been – indicated trust in the provider or NGO or was simply a means of finding care.

4.7 Decision-Making

The financial, systems, and geographic barriers identified in this study have been well-established in the literature. Their relative weight as patients and families navigate the health care system is not wholly clear, however. One study on delays in care in Africa suggests the quality of care has a higher priority variable than cost [THADDEUS 1994]. In this study, however, by frequency of mention, financial concerns were paramount. With phrases such as "long waits" and "far away" being subjective, though, it can only be said that approximately half of parents/guardians identified with these descriptors – it is difficult to speculate which was more pressing. Distance from the clinical site is linked to transportation, which typically incurs its own cost. Nonetheless, more respondents thought waiting was more difficult than transportation, suggesting families may be more able to overcome geographic barriers in seeking pediatric surgical care. Based on frequency of response, there is suggestion of a decision-making heuristic: Families are able to surmount the barrier of distance if it meant care would be provided for free or at reduced cost, for example, but they were not willing or able to pay more to have care provided closer to home.

Worry about surgical complications and fear of the unknown, mistrust of providers or health care systems, health literacy/education, and other cultural barriers are other factors that also require further exploration and integration into a decision-making model. In this sample, worries and fears appear to have been more common, but

other populations represented less well in this dataset may rank their concerns differently.

4.8 Challenges Faced by NGOs

The focus of these NGOs was to improve lives. Consequently, the surgical conditions they treated were urgent but not emergent. This still left gaps in care for many Guatemalans. The long-term effects of NGOs are not known [OZGEDIZ 2009], but the more successful they are in filling a need, the greater the chance local systems will become dependent on them and their work will become the norm [REDFIELD 2005].

In his ethnography of Médecins Sans Frontières, and recognizing the potential disconnect between physicians' and social scientists' ethical lenses, Peter Redfield raises a question applicable to this and other NGOs: Should the NGO function in an imperfect system, potentially perpetuating social norms, or act as a lever to jar political wheels into motion [REDFIELD 2005]? To this end, "a humanitarian response to human suffering… cannot escape… the historical context of conditions to which it responds" [REDFIELD 2005]. He also touches on other ethical dilemmas NGOs may face, such as the value of life versus the defense of human dignity and tensions between the NGO and local providers: Those in the national system may resent an influx of patients who suffered complications in other facilities whose physicians have since departed, and private practitioners may argue NGOs are infringing on their patient volumes and undercutting them in cost [REDFIELD 2005]. The first example in particular highlights the ethical

challenges faced by providing care to families who may not fully understand what is going on due to language barriers, limited health literacy or education, or simply being in a vulnerable position due to socioeconomic and medical need. Similarly, there are ethical concerns regarding distribution of scarce resources, privileging those already in a better position, and, even after checking their credentials, utilizing short-term (visiting) providers to render care. Volunteers and staff members in these NGOs need to respect local providers and communities and understand available resources and needs, carefully selecting the patients they serve as one way to avoid dependence on foreign aid [GREEN 2009].

4.9 Future Directions

Interviews with a more demographically-representative sample (i.e., more indigenous Maya and more rural-dwellers), further questioning on – and measurement of – fears and mistrust, and exploration of ethical issues faced by NGOs are potential areas for further work. Pooling and reevaluation of the data obtained during the 2013 National Association for the Practice of Anthropology-Occupational Therapy (NAPA-OT) Field School in Antigua, Guatemala could help to expand the data set – 16 of the 23 respondents were either bilingual or monolingual in a Maya language – but only 35% of these interviews were about pediatric surgery [BROCKINGTON 2013]. Further consideration of decision-making models for this and other populations, perhaps

organized by phase of care (i.e., seeking, accessing, and receiving care), may help the study of barriers to surgical care pass from the theoretical to the practical.

Though this study appears to be about failures – why families cannot obtain surgical care for their children, fears and mistrust, and incomplete behavioral models – it can be reframed as one about successes: how barriers may not necessarily be overcome but reduced, how NGOs inspire trust, and what health care facilities do, and not just how they fail.

4.10 Study Limitations

The principle limitations in this study stem from sampling bias. First, our study population focused on families who were those successful in overcoming at least some of the impediments to care, and thus does not mirror the experiences of others who were not successful in accessing care. Second, in order to reach these families at all, the research team worked with local NGOs providing care. With interviews being conducted within the same healthcare facility as where these organizations practiced, families may have been reluctant to be critical or appear ungrateful for their care. Third, there was some self-selection by families willing to participate: It may be possible that those who were embarrassed by their limitations, or those who would be more critical of the healthcare system or NGO, chose not to participate. Similarly, those who did participate still may have self-censored certain topics. These particular sampling biases are difficult to avoid given the research methodology.

Several additional sampling biases related to enrollment may reduce generalizability of these results. First, the sample reflects only those receiving care from an NGO; the experience of families obtaining care in public or private facilities may have been different. Second, the sample is under-representative of the indigenous Maya population in Guatemala. It was thought that direct questioning of ethnic identity would be inappropriate given the implied power dynamics, but using language (or cultural dress) as a proxy may also overestimate this demographic detail and does not allow parents/guardians to report a mixed indigenous/ladino identity as providers were permitted to do. However, the sample did reflect the typical composition of patients seeking care from the studied NGOs. Third, only about a third of the families had completed their hospital stay and had been discharged home. Families who were still undergoing screening for surgery were, understandably, less certain of what to expect during the pursuit of surgery, and may not be able to articulate views on some barriers. Fourth, as families were recruited through convenience sampling, the type of clinical problems were biased by the type of surgeons that were visiting at that time. Fifth, although American and Guatemalan primary care providers were represented, there were no American surgeons to complement the Guatemalan surgeons interviewed.

The short-term nature of data collection and limitations with the interview instrument may also have led to some barriers not being mentioned or admitted. Researcher presuppositions about what topics should be included in the instrument may

bias the data. The age of the parent/guardian, their profession, the number of children in the household, and whether multiple family members were present at the clinical site were not asked. Literacy and language fluency were not assessed. Use of the interview tool as a survey instrument for one healthcare provider may also have artificially guided or primed the subject, yielding biased responses that are not directly comparable to those who participated in live interviews. Focus groups could be a reasonable alternative means obtaining information, but may also fall to the same priming bias and additionally feature self-censoring of responses due to worry of making certain statements in front of a group of peers.

Finally, the researchers cannot ignore their own potential to influence results. One of the interviewers was a primary care physician, though this may have been revealed inconsistently to parents/guardians. Five of the healthcare providers were known to those conducting the interviews through the course of becoming familiar with the clinical sites and missions.

5. Conclusions

There are many reasons why patients fail to get the surgical care they need. In Guatemala, a strained national system has resulted in tears in the healthcare fabric – gaps for NGOs to fill. Despite this, patients and their families still face challenges. Through interviews with parents/guardians seeking pediatric surgical care from an NGO – and complemented by healthcare providers delivering this care – our study has confirmed that financial concerns were among the most common perceived barriers to care, followed by systems issues and geographic factors. Potentially-limited health literacy and education and language barriers were also mentioned by some providers but not families, underscoring the difference in populations these groups served or represented. By reporting they felt dehumanized in the public health care system or perceived foreign providers as more altruistic, some of the parents/guardians in this privileged sample alluded to a more central barrier to care and within the realm of beliefs and knowledge: fear and mistrust. Understanding the roots of these feelings may allow providers and NGOs alike to inspire trust in their work and help families develop greater self-advocacy.

To organize these barriers in this specific Central American context, we propose a revision of Irfan's Healthcare Barrier (HCB) Model to include more explicit recognition of fear and mistrust as central barriers to care, implied by Hochbaum's Health Belief Model but overlooked in other more contemporary models. This novel Framework for

Barriers to Pediatric Surgery in Guatemala (FBPSG) may only apply to this specific population seeking pediatric surgical care from an NGO in peri-urban Guatemala, but nonetheless warrants further study, particularly in oppressed populations and those with even more limited access to health services.

Future research in this population – and aiming for a more ethnically-representative sample – may further develop a care-seeking/decision-making rubric, mapping out how families encounter and respond to barriers and what outcomes they ultimately reach. Additionally, this area of research is still largely in a data collection phase, and further evidence of the burden of surgically-treatable conditions and the financial costs associated with that can be helpful in bringing about change to inadequate health policy. This paper contributes to the field by responding to a dearth of qualitative research on barriers to surgical care. It also enumerates and details some of the costs associated with pursuit of care from an NGO. Though it may not be possible to generalize these results to other healthcare systems, fostering trust in health systems and providers may be one of the most important actionable steps that NGOs are taking to help families overcome barriers to pediatric surgical care in Guatemala and make use of their needed services. Addressing individual patient fears at the population- or systems-levels can be achieved through subsidizing medical care, promoting health education, and providing inclusive, good quality medical and interpersonal care. NGOs providing surgical care in Guatemala have worked with trusted community partners and featured

multinational partnerships with foreign and domestic providers working alongside one another. It remains to be seen, however, whether trying to better integrate ladino and Maya patient populations in the same facility – potentially via collaborations between NGOs – would help to normalize care and better balance costs to the organization, or whether it would serve to further intimidate needy families and instead act as a different cultural barrier.

6. Researcher Experience

"It's all about the money," he said, rubbing his second and third fingers against his thumb.

"Yes, but…" I protested. "It's more than that," I half-pleaded, hoping that what I said was true.

Some 6 months before I was set to start my field work, a Mexican documentary-maker had already answered my research question. It was a fairly simple inquiry: Why can't children in Guatemala get the surgical care they need? And it received a simple answer. I couldn't help but think back to a cartoon on the wall of my brother's dorm room 2 decades prior: "Money makes the world go 'round."

This moment illustrated for me the central difficulty in social science research: How does one interpret the data without biasing it with presupposed answers or cherry-picking what to report? What is important? And to whom? In qualitative studies such as this, the criticism is leveled (and rightly so) that writers are selective in what they report, using only what they deem important or supportive of their own conclusions. Indeed, interpretation is in the eyes (and pen) of the interpreter; it is simply too time consuming to publish the raw data and have readers make their own conclusions. In my case, I wore the lenses of a scholar trained in biomedical sciences – specifically medicine.

In his book How Doctors Think, Jerome Groopman, a physician-cum-writer at Harvard details some of the pitfalls into which healthcare providers fall: "availability,"

mistaking likelihood of an outcome with how easily it comes to mind, "confirmation bias," using available evidence to support a diagnosis, and "diagnosis momentum," in which a diagnosis seems more and more credible as it becomes perpetuated by subsequent providers [cited in CRICHTON 2007]. In a way, my semi-structured interviews with parents were indeed doctor-patient interactions, and perhaps I had the unconscious urge to make a "diagnosis" at the end of our 15 minute encounter. With a preformed tool to guide the conversation, certain topics – e.g., monetary costs – were destined to be discussed, which increases the frequency of mention by parents/guardians and making the topic more memorable. Similarly, only the data that was provided can be pieced together; it is hard to draw conclusions with an unknown body of evidence that was untouched. Finally, as certain barriers were well-documented by other authors, it cannot be taken on faith this is true in all populations but should be challenged in each study.

During the course of my Masters thesis research, I played doctor, anthropologist, student, and interpreter; worked in unassuming clinics made of concrete and make-shift consultation rooms divided by hanging sheets; and endured cold showers, feasted on free food, and sampled local beer. A narrative account of my experience on a medical mission in rural Guatemala was published on September 23, 2013 in the campus newspaper The Duke Chronicle in my biweekly column "Urban Grizzly" about a month after my return (Appendix E). Though I had had ample experience in other Latin and

Central American countries, it was my first time in Guatemala. It was also my first time trying to apply new-to-me research methods. Consequently, despite reading textbooks on data interpretation, it was still difficult to make sense of the data, contend with the biases, and still present something that was worthwhile but not overreaching. (Imagine my surprise when I discovered there are some grounded theorists who advise not performing a literature review prior to conducting research. How this would meet IRB approval, I don't know, but the cat was already out of the bag on that one…) Out of all the components of this research effort – designing the interview instrument, preparing documentation for the IRB, conducting the interviews (without being coercive to get participants or lead them in their answers), correcting the transcripts in Spanish, coding the data, trying to make sense of it, and finally preparing a poster presentation – it is probably my field notes that are most revealing as to how I experienced my project.

To read through my field notes several months after leaving Guatemala is a bit like reviewing your childhood artwork from elementary school, lovingly preserved by your parents. Firstly, it's surprisingly decent. Sure, it might have been a bit naïve, but sometimes its observations were completely accurate. Secondly, it's often quite literal: Skies are blue, grass is green, and anything to the contrary would never make it to the page. Unfortunately, though we argue ourselves into thinking this is free from bias and "how things are," it's still just one snapshot in time. For instance, seeing a blue sky – even multiple times – misses the times when it's not (e.g., sunset, thunderstorms).

Thirdly, it's undrafted. Professional artists frequently practice sketching out elements they have trouble illustrating, and they usually mark out their design in pencil before ink or paint is applied. Children, for the most part, just draw. I found it challenging to write without passing it through a creative filter. Each entry in my field notebook was a little exercise in description, but each line could serve as its own work of art. It was hard not to try to make these notes "perfect." Indeed, I became so enamored with some phrasings that they went directly from the notebook page to my newspaper column. Trying to take notes unobtrusively on-site and then converting them into an accurate (or as accurate-as-possible) depiction without romanticizing was difficult. Similarly, trying to describe human interaction was difficult because the researcher's own frame of reference could nonetheless shape what he sees. Further, even without interacting with others, the researcher's presence is felt, and that changes behavior and thereby what is seen.

My field notes echoed some of the healthcare providers' concerns as 5 of those interviewed were involved in these jornadas or worked at the clinical sites. My cumulative experience with some of the providers was much longer than that with families, which may have unintentionally elevated their opinions as I reflected on barriers to care – another interpreter bias. Unfortunately, in my field notes, there is very little in the way of perceptions from patients; though the volume was high, the time with each individual (or family) was relatively short, and the jornada with Partner for

Surgery took place before the interview instruments were pilot-tested. As the parent/guardian sample in Guatemala and Antigua did not reflect the ethnic composition of the countryside, it would have been nice to obtain these perspectives through other means and further explore the roles of gender, age, and language.

It seems so obvious now in retrospect, but there are many steps in conducting a research study. More than I realized. There is a certain degree of comfort in planning – e.g., preparing a research proposal for IRB review, scheduling interviews – but it seems much harder with qualitative research than with quantitative research to know how long a task will take or when it is actually complete. This made time management particularly difficult. Due to my lack of experience as a field researcher, nearly every step was a challenge, especially when performed "without a net," or another person to check over the details of my work. Writer's block flourished. Even with Spanish proficiency, understanding and fully translating interview transcripts was difficult. Coding the data by hand was time-consuming, easy to make errors of classification or omission, and difficult to reanalyze. I worried that presenting the results in a succinct manner risked accusations of reporting bias. Interpreting the data, in particular, was hard, as in trying to make the results seem relevant, I sometimes overstated their implications. Alternatively, what was obvious – or well-documented in the literature – did not necessarily need as much attention. Lastly, it was hard to determine when a task

in the research agenda was wholly done, as I frequently had to go back to my codebook or recheck my "quantified" data.

Consequently, nothing was "easy" as I learned to develop and pilot test an interview tool, conduct those interviews and revise their transcripts, take useful field notes, apply grounded theory to the data analysis, and use and critique conceptual frameworks. These challenges haven't dissuaded me from doing qualitative research again in the future, but the next time, I will plan to hire an interpreter to draft the interview transcripts and use computer software such as NVivo or Dedoose. This might take some of the mystery or insecurity out of the research process for me and help ground the conclusions in fact rather than speculation.

Appendix A: Parent/Guardian Semi-Structured Interview Tool

Interview No.: _____
Date: _____
Interviewed by: _____ ☐
Notes by: _____ ☐
Data entry by: _____ ☐

(Tick box when tasks are completed.)

Informed consent has been administered: YES / NO
(If informed consent not attained, interview must not proceed.)
Length of interview: _____ minutes

DEMOGRAPHICS

1.
    a. Did you receive a surgery from a visiting medical team? YES / NO
    b. Did your family member receive surgery from a visiting medical team? YES / NO
    c. If YES, how is the patient related to you? _____
2. Age of patient _____
3. Sex of patient _____
4. Date of surgery _____
5. Type of surgery _____
6. Location of surgery _____
7.
    a. Where do you/the patient live? _____
    b. Is where you live URBAN or RURAL [CIRCLE ONE]?
8. How many people live in your house? _____
9. Do you speak another language besides Spanish? YES / NO
10.
    a. Did you go to school? YES / NO
    b. If YES, until what grade did you study? _____

ABOUT THE NEED FOR SURGERY

11. How long was it between when you realized surgery was needed and when it was received? _____
12. What were the symptoms that you noticed? _____
13.
    a. Did the symptoms affect daily activities and quality of life for you/the patient? YES / NO

b. If YES, how so? _____

14.
   a. Did you seek medical care for this condition in another place? YES / NO
   b. With whom? _____
   c. When did you first see this provider? _____

15.
   a. Did you/the patient have any diagnostic tests (eg, lab tests or x-rays)? YES / NO
   b. If YES, what kind? _____

16.
   a. What do doctors call the medical problem/illness from which your family member suffers?

      _____
   b. Do you or others in your community have another name for it? _____

ABOUT RECEIVING THE SURGERY

17. How did you find out about getting surgery from *[this organization]*? _____
18. After enrolling with this organization, what were the steps that you took to get the surgery? (e.g., required forms, diagnostic tests, clinical visits) _____
19.
   a. Did you have to travel far to get here? YES / NO
   b. If YES, how long was the journey? _____
20. How did you travel? [CIRCLE ONE]
   Bus, taxi, private car, shuttle provided by the surgical team, other _____
21. Who paid for the journey? _____
22.
   a. Did you have to spend nights away from home to receive surgery? YES / NO
   b. If YES, where did you stay? _____
23. Did you pay for your stay? _____
24. Did the organization who provided the surgery give you assistance with food, travel, or lodging?
   YES / NO
25. Did you pay for your surgery? YES / NO
   a. If YES, How much? _____Q
   b. In the case of donation, how much do you hope/plan to give? _____
26.
   a. Did you encounter other costs in receiving your surgery? YES / NO
   b. If YES, For what? _____
   c. If YES, How much? _____Q

AFTER THE SURGERY – If surgery has not yet been completed, SKIP to QUESTION 31

27. Did you/the patient receive care from the surgical team after your surgery? YES / NO
28.
    a. Did you/the patient receive instructions about how to care for the wound after returning home? YES / NO
    b. If YES, what did they tell you to do? _____
29.
    a. Were you able to understand and follow these instructions? YES / NO
    b. If NO, what made it difficult? _____
30.
    a. Do you think that the surgery your child received was good?
    b. Why or why not?

YOUR FEELINGS ABOUT THE SURGICAL PROCESS

31.
    a. Do you think that the assistance provided before and after the surgery [if surgery is complete] was good? _____
    b. How so? _____
32. In respect to your medical problem, including recuperation, what has been the most difficult part in dealing with this problem? _____
33. Was there anything that worried you about surgery? _____
34. What would be your advice to someone else in your family or community who was suffering from the same problem and needed surgery? _____
35. What could be improved in the process of receiving surgery based on your experience? _____
36. How do you feel about receiving surgery from foreigners? _____

CONCLUSIONS

37. Do you have anything else you would like to add about your experiences? _____

Appendix B: Healthcare Provider Semi-Structured Interview Tool

Interview No.: _____
Date: _____
Interviewed by: _____ ☐
Notes by: _____ ☐
Data entry by: _____ ☐

(Tick box when tasks are completed.)

Informed consent has been administered: YES / NO
(If informed consent not attained, interview must not proceed.)
Length of interview: _____ minutes

DEMOGRAPHICS

1. Are you involved in the provision of surgical care at [this organization]? YES / NO _____
    a. What is your official role (eg, surgeon, nurse)? _____
    b. How long have you been working/volunteering here? _____
    c. How long have you been practicing? _____
2. Age of provider _____
3. Gender of provider _____
4. National origin _____
5. Country of residence (if different from #4) _____
6. ***For Guatemalan health care providers:***
   OPTIONAL: Would you call yourself INDIGENOUS or LADINO [CIRCLE ONE]? _____

YOUR OBSERVATIONS

7. How did you come to be involved with this organization for surgical care? _____
8. How would you characterize the population served by this facility? _____
    a. How are your patients here different from those you treat in other communities (or your home country, if you do not practice in Guatemala)? _____
9. What are the types of surgical problems that you see in this population? _____
    a. Would you consider many of these surgeries "emergent" (ie, needs to happen very soon)?
       YES / NO _____
    b. Would you consider many of these surgeries "vital" (ie, needs to happen for quality of life)? YES / NO _____
10. *For surgeons:* What surgical procedures are you using to correct these problems? _____
    For other healthcare providers: What is your role in helping correct these problems? _____

11. ***For surgeons:*** Do you find that what you're able to do here is different than the technique you'd prefer to use? YES / NO
    a. If yes, how? _____

    For other healthcare providers: Do you find that what you're able to do here is different than what you'd prefer to do in the community where you practice? YES / NO
    b. If yes, how? _____
12. What kinds of worries or concerns do you see in patients' families? _____
13. How is follow-up care provided for your patients? _____
    a. Have you had any difficulties with patient or caregiver adherence? YES / NO _____
    b. If yes, what? Can you speculate why? _____
14. Have you had any problems with patients or their families expecting more than you can provide?
    YES / NO
    a. If yes, what? _____

YOUR EXPERIENCES

15. How far away do these patients tend to live? _____
16. Given the specific characteristics of your patient population (eg, poor access to transportation, limited finances, need for a particular family member to be present), have you had to change what you would like to do (eg, change timing of surgery)? _____
17. ***For surgeons:*** How are patients' surgical needs first identified? By whom? _____
    For other healthcare providers: Did any of your patients previously see a local traditional healer (eg, huesero) or other medical professional? YES / NO
    a. If yes, what kind of provider was it, and where did they see him/her? _____
18. What challenges have you encountered while providing care with this organization? _____
    a. Were you able to surmount any of these challenges? YES / NO
    b. If <u>yes</u>, how? _____
    c. If <u>not</u>, how did it impede your work? What suggestions do you have (for your organization) for overcoming these challenges? _____
    d. In your experience, have there been any changes in the way this organization functions that has helped overcome these challenges? _____

YOUR SUGGESTIONS

19. What advice would you give a Guatemalan family who will be seeking out surgical care for a child? _____
    a. Would your advice be any different for a family outside of Guatemala? _____
20. What advice would you give a healthcare provider who wanted to provide care here, either permanently or as a volunteer? _____
21. What changes do you think need to come about to make surgical care better in Guatemala? *[Probe for NGOs vs national system, as needed.]* _____

CONCLUSIONS

22. Do you have anything else you would like to add about your experiences with surgery or surgical care in Guatemala? _____

Appendix C: Codebook Codes (Parent, Child, Grandchild)

1. **Surgical conditions**
    a. Symptoms
    b. Impact on life
    c. Types of conditions
    d. Problems that cannot be addressed by NGO (limitations)
    e. Causes of problems (e.g., malnutrition, heavy physical labor)
    f. Acuity of surgical problems (e.g., vital/emergent, urgent, "routine")

2. **Costs**
    a. Transportation
        i. Monetary cost
        ii. Type
        iii. Distance (from surgical care center and/or "in-field" mission site)
        iv. Availability (of vehicles or other means of transport)
        v. Accessibility ("remoteness" of location; of vehicles themselves)
        vi. Safety (of transport or moving within/between communities)
    b. Food
    c. Lodging
    d. Of labs
    e. Other costs
    f. Of procedure itself
    g. For follow-up
    h. Opportunity cost (e.g., missed work)
    i. Perceived "ability" to pay
    j. Donations or in-kind services
    k. Cost as prohibitive barrier to pursuing a referral or treatment plan

3. **Access to health services**
    a. Finding out what's available
    b. Lack of insurance
        i. Services only available to workers (IGIS)
        ii. Other
    c. Provided "free" national services
    d. Private health services
    e. NGOs

f. Human rights
    i. To health
    ii. To be treated with respect
g. Other attempts at care/other experience
    i. "Traditional" or "alternative" medicine (e.g., herbs, bone-setters)
    ii. Other facilities (public, private)
    iii. Referrals
    iv. Support groups
    v. Failure of these attempts (e.g., antibiotics in biomedicine, other dead-ends)
    vi. Previous experience with surgery
h. Steps in obtaining care from NGO
    i. Workup (labs, radiography, etc.)
    ii. Other steps

4. Expectations of surgery

a. Timing of surgery
b. What needs surgery (i.e., what they view or have been told is a surgical issue)
c. What can be done
d. Surgery as panacea
e. Preference for certain type of provider
    i. Gender
    ii. Age
    iii. Nationality
    iv. Ethnicity
f. Reasons for pursuing care

5. Experience with surgery

a. How patients found out about jornada/NGO
b. Waiting time (and what was too much/long)
c. Delays in steps of treatment-seeking
d. Awaiting a phone call
e. Receiving conflicting information (diagnosis, steps/scheduling)
f. Problems with patient adherence pre-op
g. Post-operative care
    i. Prior to leaving hospital/facility
    ii. Post-op instructions
    iii. Follow-up care (appointments)

h. "The hardest part" (e.g., waiting during surgery)

6. **Provider experience of surgical missions**
    a. Knowing limitations
        i. Personal
        ii. System (protocols, planning)
    b. Quality of life
        i. For providers "in the field" (e.g., volunteers *on jornada)*
        ii. For providers in hospitals (e.g., surgical residents)
    c. Teamwork
    d. Financing
        i. Medical missions (e.g., trips abroad)
        ii. Working with impoverished/needy (e.g., having to work 2+ jobs)
    e. Fatigue
    f. Networking
        i. Provider recruitment
    g. Specialized providers
        i. Lack of capacity to deal with certain concerns
        ii. "Patient sharing" between NGOs (e.g., referrals)

7. **Services and volume of patients**
    a. Volume of patients
        i. At screening
        ii. To be operated on
    b. Provider perceptions of patients
    c. Procedures
        i. In office (or field clinic)
        ii. In OR
        iii. Who performs (or can perform)?
        iv. Differences in techniques between locations/sites
    d. Other services
        i. Nutrition program (for malnourished surgical candidates)
        ii. Pre-op evaluation/risk stratification

8. **Resources for providers**
    a. Facilities
        i. Number and location of facilities
        ii. Number of available providers and their specialties

iii. Supplies and equipment
    1. Consumable supplies
    2. Permanent equipment
iv. Utilities (eg, electricity, running water)
v. Funding of care sites (NGOs, hospitals, etc.)
    1. By foreigners
    2. By other Guatemalans (excluding recipients of care)
    3. By recipients of care
    4. By government
    5. By private companies/entities

b. Accommodations
c. Allied services (e.g., ultrasound)
d. Other staff/personnel (e.g., secretaries, social workers)

9. Perceptions of quality of care

a. Subjective perceptions
    i. Of providers and staff (e.g., "nice," "experienced")
    ii. Of care itself
    iii. Personal criteria/geshtalt for determining this
b. Objective measures
    i. Checking provider credentials (by NGO)
    ii. NGO quality
    iii. Overestimating ability/capacity
        1. By NGO
        2. By provider
    iv. Unfamiliarity with diseases and conditions in the developing world
    v. Bad outcomes/complications (e.g., wound dehiscence, infection)
    vi. Patient "ownership"
    vii. Impact on/improvement in quality of life

10. Patient confidence

a. Trust
    i. In local (Guatemalan) providers
    ii. In foreign providers
    iii. In NGO
    iv. Perceived authority/experience
        1. Age of provider (as a proxy for experience)
b. Fatalism

c. Faith
    i. In G-d/Jesus
    ii. In providers
d. Fears
    i. Of anesthesia
    ii. Of procedure
    iii. Of other peri-operative problems
    iv. Of pain
    v. Of death
    vi. Of organ harvesting/illegal activities
e. Other worries
f. Gratitude

11. Health literacy

a. Patient perspectives
    i. How they "knew" there was a medical/surgical problem
    ii. (Not knowing) name of condition
    iii. (Not knowing) name of procedure
    iv. Other forms of medical illiteracy (separate from linguistic illiteracy)
    v. Explanations
b. Provider perspectives

12. Language barriers

a. Provider experiences
    i. Personal abilities/limitations
    ii. Languages spoken by other staff and volunteers
b. Patient experiences
    i. (Assumed) indigenous status based on language
    ii. Inability to communicate
    iii. Facilitators to communication (eg, family members, multilingual staff)

13. Decision-making

a. Gender roles
b. Minors
c. Influence of other family members/community

14. Monitoring and evaluation

a. Feedback
    i. To providers
    ii. To other staff (e.g., nurses, health promoters)
    iii. Evaluation of program's outcomes (quality improvement)
b. Disagreements
    i. Between providers
    ii. Between NGOs

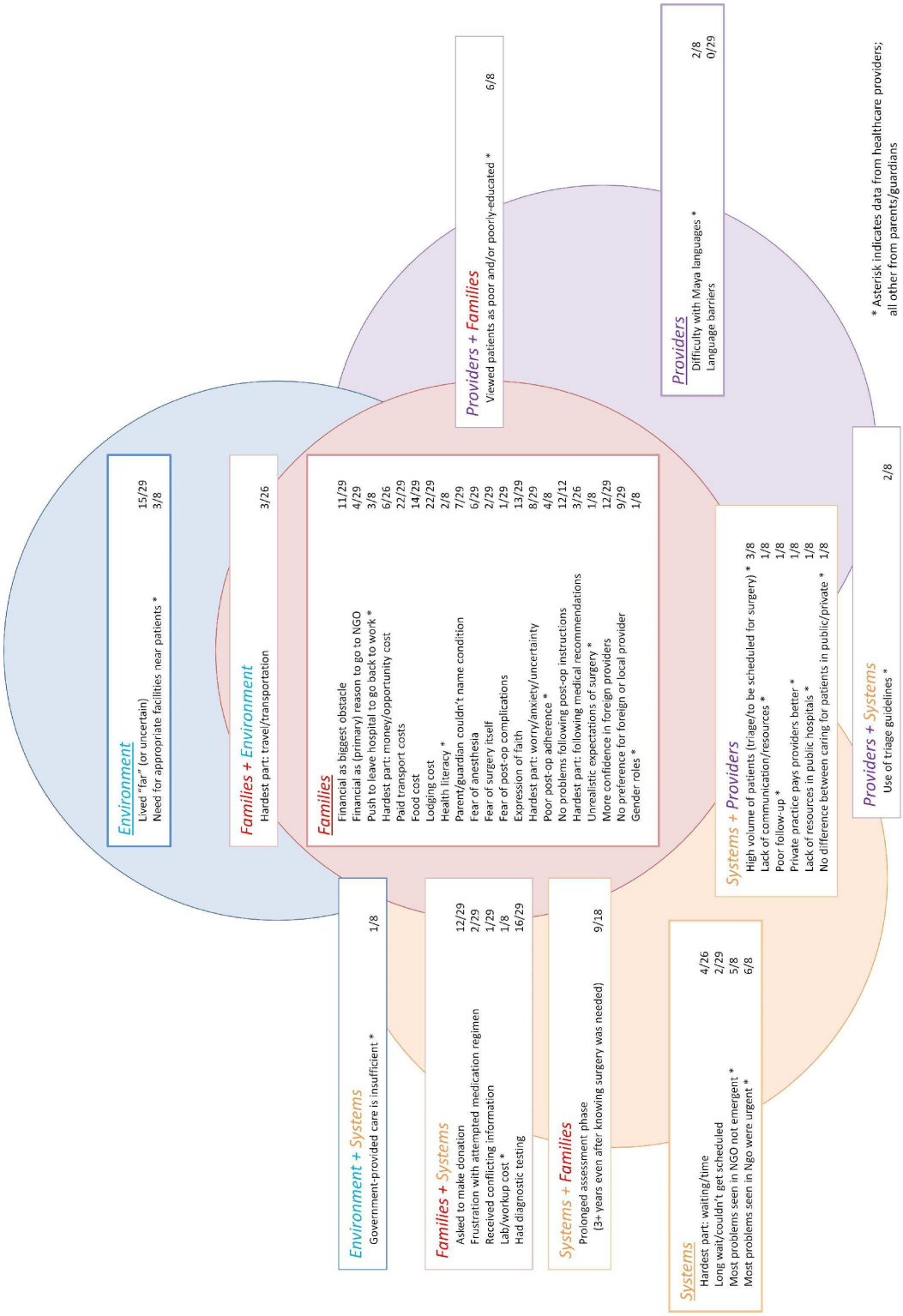
15. How to improve care (provider and family recommendations)

a. In NGO
b. In Guatemala in general
c. Things patients/families can do

16. Education

a. Formal (classroom studies)
b. Informal (job training, life experience)

Appendix D: Raw, "Quantified" Data Mapped onto HCB



Appendix E: “On a Mission,” The Duke Chronicle

Effectively, we just built a hospital. It wasn’t the mortar and brick we carried, but the smaller details that converted a concrete husk to a home for health: pills, stethoscopes, alcohol swabs, bedsheets… As over 100 would-be patients waited outside in the morning sun (many had been there since before sunrise), we scrambled to unload plastic crates from the vans and organize triage, exam, and procedure rooms, a laboratory and pharmacy, and waiting spaces.

The building itself was a largely empty shell on a still- functioning military base in north central Guatemala, about 20 kilometers from the Mexican border. I suspect it was an army barracks at one time, with 5 dorm-size rooms off the entry hallway, a large, undivided great room, and bathroom stalls and a group shower in the back. It now served as the health center for the town of Playa Grande – about 20 minutes down the dirt road but nowhere near a beach – and its surrounding residents. Inside, there were a couple of mismatched gurneys, 2 sets of rusting tri-fold room dividers, and a glass-faced bookcase containing old editions of key medical texts (in duplicate). The walls were covered with public health posters on hand-washing and mosquito-borne illnesses, as well as epidemiologic statistics on various diagnoses and provider schedules. Though it possessed neither the sterile whiteness or perpetually-busy hum of an American hospital, it still served its duty. With our team members – American and Guatemalan healthcare providers, nurses, interpreters, social workers, and outreach coordinators,

local health promoters, and government workers – moving quickly to fill in the functional gaps, it soon became difficult to tell what had been present and what we had imported. And within 15 minutes, the line started moving and we set to a different kind of work: evaluating unmet surgical need among the local men, women, and children.

Now "local" is a relative term, and many would-be patients left their homes at 2am to travel to see us. It had been years since the last jornada (medical mission) had visited, and of course children were born and new health conditions developed in the interim. Some heard we were coming through newspaper or radio ads, but most learned about us through their local health promoters and word of mouth. They came to us because the effort and expense to travel several hours away to a national hospital was just too great. And though our later work would have us working in a school and, separately, a small, unused hospital ward, it struck me that besides the barriers of cost and distance, these particular patients also potentially had to overcome the fear of entering a military base. Guatemala's civil war – ignited by the United States and fought between the national military and both rural peasants and intellectuals – ended 17 years ago, but posters of Los Desaparecidos ("the disappeared," or those kidnapped and murdered by the government) still line certain blocks in the capital.

As an American, I was privileged not to have this fear, and, to be honest, I even took some joy in not knowing what to expect. We had driven from Antigua, a haven for tourists in colonial style, through Guatemala City, and then north, north, north in a 2

vehicle caravan. Twenty-one people filled 19 seats, and the remaining space (including the roof) was packed with supplies: portable fans, granola bars, and purified water to provide some comfort as we worked, and even books for the children and breast pumps for the new mothers we were about to meet. The mixed aroma of corn and burning smoke from poorly-ventilated houses along the road punctuated the journey, as did moody swings in the weather: sun-kissed green mountains were obscured with grey skies and heavy rains and then back again. The purported 8 hour drive was actually 11, with the last couple of hours on dirt roads without streetlamps. Having never seen our destination before, even in pictures, I felt as if I were slipping into the jungles of Joseph Conrad's Heart of Darkness. I was happy to discover there was a town at the end of our route, with a legitimate hotel (a couple, in fact). A late dinner and early wake-up call followed, and a few hours later, we found ourselves at work.

Somehow I hadn't expected us to be working indoors. Instead, I had envisioned us erecting tents in the middle of a field somewhere. My quiet naïveté was cute but quickly banished. Slowly at first, and then with increasing confidence and efficiency, our 3 primary care providers, volunteers from South Carolina, evaluated gynecologic, internal medicine, and pediatric concerns in their respective rooms. Referrals for surgery were made and sometimes medications (antibiotics and NSAIDs) were given. Cleft lip and palate in the children was common, a consequence, in theory, of the malnutrition that plagued the country, as were hernias and orthopedic concerns from physically-

demanding work. Another team of workers performed IVAA, a procedure to paint the cervix with vinegar, looking for cells suggestive of cancer. At times it was a bit overwhelming, but we all fulfilled our respective roles. We were neither building walls, nor tearing them down. Together, we just lowered them a little, hoping to make a difference. Caked in sweat and grime, exhausted, and thinking about a cold shower, at the end of the day, I couldn't have been happier.

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